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ABSTRACT

The final report describes the accomplishments of the Carolina Institute for Research on Early Education for the Handicapped, a center sponsoring ecological research on families of young handicapped children. An introductory section outlines the institute's mission and administration. Eight research projects are detailed in as many chapters. Research focused on the following topics: characteristics of successful parents of moderately/severely handicapped children, families at risk, family networks and the development of adaptive behavior, parent involvement for programs of handicapped children, parental perspectives of preschool mainstreaming, child assessment, curriculum development, related research for moderately/severely/multiply handicapped infants, and Project CARE (a study comparing center- and home-based early intervention). Project dissemination and training activities are summarized, and its impact on the field of early education for the handicapped is anayzed for each of the research projects. (CL)

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THE CAROLINA INSTITUTE FOR RESEARCH ON EARLY EDUCATION FOR THE HANDICAPPED

Final Report

James J. Gallagher, Director and Principal Investigator

and

Jean W. Gowen, Coordinator

Frank Porter Graham Child Development Center
University of North Carolina at Chapel Hill

June 1982

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THE CAROLINA INSTITUTE FOR RESEARCH ON EARLY EDUCATION FOR THE HANDICAPPED

Abstract

The Carolina Institute for Research on Early Education for the Handicapped (CIREEH) was a multidisciplinary and longitudinal research program that addressed two strategies of importance to preschool handicapped children and their families. CIREEH has determined to address problems that will be (1) of major significance, (2) beyond the capability of individual investigators, (3) multidisciplinary, and (4) able to move knowledge to educational action. The approaches which addressed major Special Education Services priorities were:

I. Identification and evaluation of significant child and family variables in early intervention of the handicapped. This approach consisted of a program of descriptive studies focusing on:

   a. the role of families in the prevention of handicapping conditions,

   b. the variables affecting the professional-program-parent interaction in education for the preschool handicapped,

   c. the variables associated with progress and child outcome in early education for the handicapped.

II. Development and evaluation of intervention strategies and materials to prevent or ameliorate handicapping conditions. This approach incorporated two major intervention efforts, one with the mildly handicapped and the other with the severely handicapped to:

   a. compare two strategies for preventing mild handicaps--a parent education program and a day care plus parent education program.

   b. design and evaluate curricular strategies to maximize development of severely handicapped children.

III. Development and dissemination of products resulting from these two research approaches. These product included:

   a. reports of research results to the scientific community for its information and critique.

b. Papers and other presentations which synthesize knowledge from CIREEH research with other knowledge in the field and are prepared for varied audiences.

c. A curriculum for severely/multiply handicapped infants.

IV. Training for undergraduate, graduate, and post graduate students in the various aspects of multidisciplines. This training included planning research, data collection and analysis, and reporting of results. The training program also included seminars and colloquia.

TABLE OF CONTENTS

Page

Part I: Mission and Organization of the Institute

Chapter 1 -- Introduction 1

Chapter 2 -- Administration Organization 8

Chapter 3 -- Personnel 12

Part II: Description of Research Projects

Chapter 4 -- Characteristics of Successful Parents of Moderately/Severely Handicapped Children . . 18

Chapter 5 -- Families at Risk 28

Chapter 6 -- Family Networks and the Development of Adaptive Behavior . . . 43

Chapter 7 -- Parent Involvement for Programs of Handicapped Children 58

Chapter 8 -- Parental Perspectives of Preschool Mainstreaming 76

Chapter 9 -- Child Assessment Project 85

Chapter 10 - Curriculum Development and Related Research for Moderately/Severely/Multiply Handicapped Infants 106

Chapter 11 - Project CARE 120

Part III: Dissemination and Training

Chapter 12 - Dissemination 139

Chapter 13 - Products and Presentations 146

Chapter 14 - Research Training Activities 187

Part IV: Impact

Chapter 15 - Impact 202

Appendices

Appendix A - Project CARE Assessment Procedures . . . .

Appendix B - CIREEH Products and Presentations . . . .

1. Curricula, Manuals, and Instruments
2. Books, Chapters, and Monographs
3. Articles, Reviews, and Proceedings
4. Other Publications
5. Unpublished Papers and Experimental Versions of Assessment Instruments
6. Conference Presentations

(See Chapter 13 for a list of these materials. They are not bound with this report.)

CHAPTER 1

Introduction

The Carolina Institute for Research on Early Education for the Handicapped (CIREEH) was designed to provide a new generation of research and related activities to answer some of the important needs of handicapped children and their families.

A stage had been reached in the long evolution of research and intervention efforts in the special education field that demanded this new generation of research. At this point, research had passed through four main stages:

1. Early intensive case studies of individual children (Itard, 1932; Freud, 1938);
2. Differentiating characteristics of various handicapped groups (Bateman, 1965; Cruickshank, 1971; Dunn, 1973; Gallagher, 1971);
3. Broad program impact evaluations of the utility of various organizational strategies or special programs (Goldstein, Moss, & Jordan, 1965; Kirk, 1958; Skeels, 1966);
4. A limited number of systematic attempts to synthesize available knowledge and develop special program materials for the handicapped (Goldstein, 1974; Hobbs, 1975; Meyer, 1970).

While these past efforts had taught us much, they had each, in turn, reached their limitations. Translation of their findings into actions had been difficult--and sometimes inappropriate--because much of the research had been fragmented and incomplete. Yet action was overdue.

Following World War II, state and federal resources had increased markedly to help handicapped children achieve their potential and become integrated with society (Gallagher, Forsythe, Ringelheim & Weintraub, 1975). Public policy had outrun current professional sophistication and ability to carry out its intent. These problems pervaded the field of early education for the handicapped. They could not be solved by a research investigator acting alone, nor by a loose or scattered confederation of scientists.

What was needed was a new generation of research to attack these problems through longitudinal studies, investigations involving complex developmental situational interactions, and closely coordinated efforts grouped around a central topic.

The central topic selected by CIREEH was the families of handicapped children. The contribution of parents to the social and cognitive development of their children had been well documented (Hess & Shipman, 1965; Levenstein, 1970; Goodson & Hess, 1975; Heber & Garber, 1975; Ramey, Beckman-Bell, & Gowen, 1980). More specifically, the necessity of involving parents directly in their child's educational program had been demonstrated experimentally (Bronfenbrenner, 1975; Karnes & Teska, 1975; Lovaas, Koegel, Simmons & Long, 1973). For handicapped children, such parent involvement had been mandated by law (P.L. 94-142). Both educational practice and legal precedent, then, had recognized the family as an integral part of educational programs for young handicapped children.

An increasing emphasis on deinstitutionalization and on parent involvement in educational programs had implied that families of handicapped children must have the ability and resources, not only to function adequately as families, but also to take on these additional roles and educational demands. Knowledge of ways to strengthen the functioning of families of handicapped children, and of the impact of educational policy decisions on family functioning, was, however, seriously limited.

In studying families, CIREEH investigators chose to work within an ecological model of human development. Such a framework assumes the contextual nature of human development and suggests that meaningful and lasting intervention are possible only when the personal, interpersonal, social, demographic, and ideological context of the individual are examined (Garbarino, 1977).

The focus of CIREEH family research has been on the family system and, particularly, on the interaction of the family system with other systems and ecological levels in the family's environment. During the past five years, CIREEH investigators have studied various aspects of the ecological environment of the handicapped child. These studies will be described in chapters 4 through 9 of this report.

Although the family was selected as the central topic for CIREEH research, the need for research on assessment methods and curricula was recognized. The need was most apparent in the area of the assessment and education of severely and multiply handicapped infants.

Research carried out by CIREEH addressed these problems through closely coordinated efforts grouped in a framework of two research approaches which focused on two diverse populations.

Overview of Research Plan

The two major approaches were descriptive and intervention studies. The descriptive studies examined handicapped children and their families in a variety of settings, particularly in interaction with professionals attempting to aid their situation. The intervention studies attempted to directly add to the resources and competencies of the child and other family members and to evaluate that effort.

There were two major populations included in the program of research. The first population was of children classified as moderately or severely handicapped whose problems are chronic and threaten to be a serious issue for the remainder of the child's life, with consequent stresses on the family unit. The second population was of children considered to be at risk for mild handicapping conditions due to socioeconomic factors.

The research program is presented in Table 1-1. One dimension of this matrix focuses on the two general populations: at risk/-mildly handicapped, and moderately/severely handicapped. The other dimension reflects the nature of the research, that is, descriptive studies and intervention studies.

Major Approaches

The program of descriptive studies focused on:

1. The role of families in the presention of handicapping conditions.

2. The variables affecting the professional-program-parent interaction in education for the preschool handicapped.

3. The variables associated with progress and child outcome in early education for the handicapped.

The two major intervention efforts, one with the mildly handicapped and the other with the severely handicapped, were designed to:

Table 1-1

The Organization of CIREEH's Program of Research

Approaches	Populations	
	At Risk/Mildly Handicapped	Moderately/Severely Handicapped
Descriptive Studies	Identification of Families at High Risk for Children with Mild Handicaps (Craig Ramey)	Family Studies: Parent Involvement in Programs for the Preschool Handicapped (Ron Wiegerink) Characteristics of Successful Parents of Moderately/Severely Handicapped Children (James Gallagher) Families at Risk (Marie Bristol) Parental Perspectives of Preschool Mainstreaming (Ann Turnbull)
	The Network of Family Relationships and the Development of Adaptive Behavior (Earl Schaefer)	
		Child Assessment Project (Rune Simeonsson)
Intervention Studies	Project CARE (Craig Ramey, Joseph Sparling and Barbara Wasik)	Curriculum Development and Related Research for Moderately/Severely Handicapped Infants (Ken Jens and Nancy Johnson)

1. Develop and evaluate parent education strategies to maximize the family's role in successful prevention of mild handicaps.

2. Compare the effects of two types of intervention, day care plus parent education and parent education only.

3. Design and evaluate curricula strategies to maximize development of severely/multiply handicapped children.

Mission of the Institute

The mission of the Institute was to study the problems which it had identified--the needs of families, assessment, and curricula--in such a way as to assure movement of knowledge into practice.

To accomplish this mission of moving knowledge into action, the Institute had the following goals:

1. Produce a variety of products which would be of value to practitioners, researchers, and parents of handicapped children. These products were to include research reports, state-of-the-art reports, literature reviews, assessment instruments, and a curriculum.

2. Provide opportunities for graduate students from diverse fields to become interested and involved in research and program development for handicapped children and their families.

3. Disseminate, through a variety of media, information and products resulting from CIREEH studies to a wide audience including researchers, practitioners, parents, and policy-makers.

The activities of the Institute, in its efforts to meet these goals, are described in subsequent chapters of this report. The overall organization of the Institute and its personnel are described in the next chapter. The research studies are described in chapters 4 through 11, and the resultant products are listed in chapter 13.

Activities which addressed CIREEH's second and third goals, dissemination and training, are detailed in chapters 12 and 14. The impact which CIREEH has already had on the field, and an outline of anticipated future effects, is discussed in chapter 15.

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CHAPTER 2

Administrative Organization

The smooth operation of a multi-investigator research institute, which involved a complex set of closely coordinated research studies, required a carefully structured and implemented plan. CIREEH's administrative organization provided for long-range planning, short-term decision making, administrative accountability, and quality control.

The organizational structure of CIREEH reflected the two major research populations (mildly handicapped and moderately/-severely handicapped) as shown in Figure 2-1. This component organization is useful in understanding how decisions were made in the Institute.

Long-Range Planning

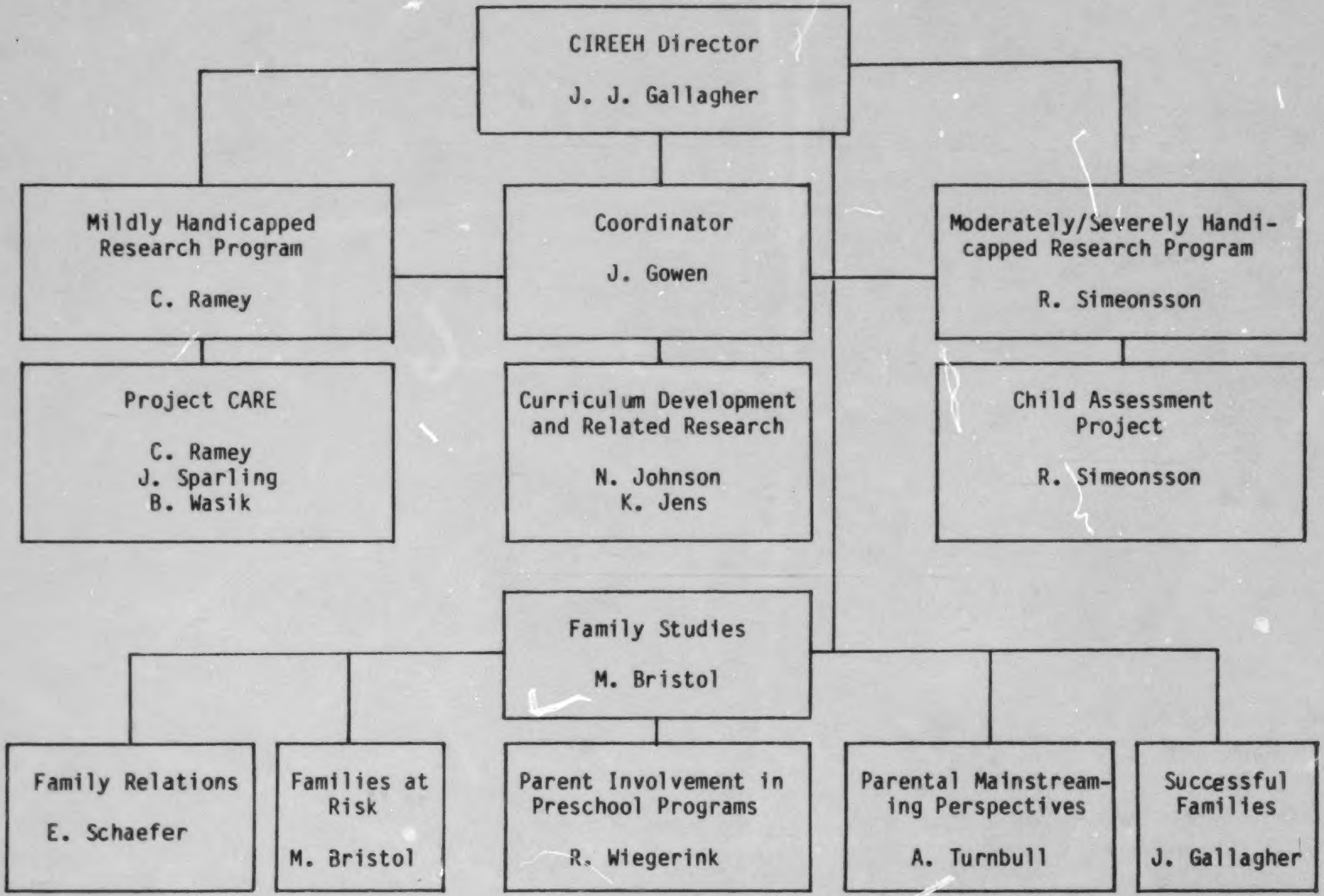
Advisory committee. CIREEH established an Advisory Committee to provide program review and guidance for its overall research efforts. The members included outstanding and nationally-known scholars in special education and related fields and both local and national consumer representatives. (The members of the Advisory Committee are described in Table 3-2 in Chapter 3.)

The Committee met, as a group, five times: in the Fall of 1977, in the Fall of 1978 to offer counsel regarding the reorganization necessitated by Ira Gordon's death, in the Spring of 1979, in the Spring of 1980, and in the Spring of 1981. Some members of the Committee visited more frequently for consultation purposes. CIREEH profited greatly from the advice and counsel of its Advisory Committee.

Seminars and meetings. A number of professional meetings are sponsored by the FPG Center in which research, program development and policy issues are discussed. The meetings range from small informal discussion groups to formal presentations. Presentors include people from a number of fields from both the University of North Carolina and other institutions. CIREEH investigators participated in many of these meetings as presentors, discussants and audience. These meetings provided a vehicle for CIREEH to relate its efforts to a broader area of knowledge, practice and policy regarding child development, education and family services.

Figure 2-1

CIREEH Component Organization



In addition to participating, when appropriate, in these seminars and colloquia, CIREEH staff met on a regular basis to present CIREEH research findings, discuss issues related to CIREEH research, and seek ways to synthesize knowledge resulting from CIREEH projects. These meetings provided CIREEH investigators ongoing critique and feedback regarding their research endeavors.

Short-Term Decision Making

As Figure 2-1 illustrates, coordination within the two research programs was assured by the associate directors, Drs. Ramey and Simeonsson, and assistant director, Dr. Bristol. Assisted by other CIREEH investigators, they made daily management decisions concerning their projects. They also assisted the director, Dr. Gallagher, in making long-range scientific decisions guiding the Institute. They were facilitated in this effort by input from the Advisory Committee. The overall responsibility for coordinating Institute activities rested with the coordinator, Jean Gowen, in conjunction with the director, associate and assistant directors. The director, Dr. Gallagher, retained the ultimate responsibility for the overall scientific direction and program management of the Institute.

The mechanisms for planning and decision making in the total program of research were, as follows:

a. Meetings of the associate and assistant directors with investigators of projects within their program (i.e., the Mildly Handicapped Program, the Moderately/Severely Handicapped Program and its sub-section, Family Studies) to discuss management and program progress.

b. Regular meetings of all major CIREEH investigators to discuss progress, to prepare dissemination strategies and to discuss ways in which knowledge resulting from individual projects could be synthesized.

c. Meetings of the director, associate and assistant directors, and coordinator to make overall management decisions and to coordinate information from various Institute components for overall Institute planning and decision-making.

Administrative Accountability

The smooth administration of CIREEH depended on its organizational setting within the University of North Carolina at Chapel Hill and how management tasks were allocated.

Organization Placement. Organizationally CIREEH was placed within the FPG Center because: a) the FPG Center was already engaged in similar work; b) the FPG Center already had established staff and working relationships with other key University components that shared in the work of CIREEH--notably the School of Education and the Division for Disorders of Development and Learning (DDDL), c) the FPG Center already had a management support staff to provide experienced administration for CIREEH from the outset, and d) placement within FPG gave CIREEH staff direct access to the resources of the Division of Health Affairs where multidisciplinary research efforts are endorsed and encouraged.

Allocation of Tasks. The business management tasks of CIREEH were allocated to two levels, the Institute level and the University level. At the Institute level, all expenditures of funds, all personnel transactions and a wide variety of other administrative transactions necessary to operate the Institute were initiated as requests to the University which acted on these requests. Accounting records were kept by both the Institute and University. As a major organizational unit within the University, CIREEH needed management assistance to help comply with University and funding source policies and procedures. For the FPG Center, such assistance was provided by the FPG Business Office. As a component of the FPG Center, the CIREEH Institute was supported and assisted by the Business Office. The overall responsibility for Institute administration management rested with Rachel Windham, FPG Administrative Manager.

Quality Control. Four types of review were employed by the Institute to assure that its programs maintained a high standard of quality:

1. Annual meetings of the Advisory Committee to review Institute performance;

2. Regular meetings of project investigators with their support staff, to review performance;

3. Regular meetings of all CIREEH investigators to review progress within the Institute;

4. Annual review of each project's proposed research plan by the director, associate and assistant directors, and coordinator.

CHAPTER 3

Personnel

To accomplish the mission it had set for itself, CIREEH assembled a multidisciplinary research team. The investigators who headed the CIREEH research projects brought to their tasks several years of cumulative experience in research and clinical work.

During its first year, CIREEH was fortunate to have as one of its co-directors and principal investigators Dr. Ira J. Gordon. CIREEH staff, along with the entire early childhood research education community, was saddened by the sudden death of Dr. Gordon in the fall of 1978. During the year that he was with CIREEH, he enriched its efforts with his scholarly and humanitarian perspective and personal vigor.

During the remaining four years, Dr. James J. Gallagher, the other co-director and principal investigator, directed the Institute. The investigators who carried out the research programs are listed in Table 3-1. As can be seen by this table, this research team represents a number of fields. Among them they hold appointments in the Divisions of Special Education, and Human Development and Psychological Services, in the School of Education, the Department of Maternal and Child Health in the School of Public Health, the Department of Psychiatry in the School of Medicine, and the Department of Psychology. The backgrounds of these investigators are varied and rich in research, administrative, and clinical experience. Prior to their work with CIREEH, various members of this research team had had experience conceptualizing and administering large scale research efforts on the education of handicapped and at risk children and their families, administering research training programs for new scholars in the field of special education, designing and administering technical assistance programs for practitioners in special education, conducting research on varied aspects of early education of the handicapped, teaching young handicapped children, and conducting diagnostic assessments of handicapped children.

The director of the Institute and the investigators were assisted in their efforts by three management groups headed by the coordinator, business office manager, communications director, and data analysis manager. These support personnel are also listed in Table 3-1. Their responsibilities and the overall organization of the Institute are described in Chapter 2 on administrative organization.

Table 3-1

CIREEH Personnel

Name	CIREEH Position	Other Positions
Administrators:		
James Gallagher	Principal Investigator and Director; Investigator, Successful Parents Project	Kenan Professor, School of Education
Craig Ramey	Associate Director and Investigator, Project CARE	Associate Professor, Psychology; Senior Investigator, Longitudinal Program, FPG Center
Rune Simeonsson	Associate Director and Investigator, Child Assessment Project	Professor of Education, School of Education
Marie Bristol	Assistant Director and Investigator, Families at Risk	Research Assistant Professor, Division of T.E.A.C.C.H., Department of Psychiatry, School of Medicine
Jean Gowen	Coordinator	Doctoral Student, School of Education
Investigators:		
Donna Bryant	Investigator, Project CARE	
Kenneth Jens	Investigator, Curriculum Development Project	Clinical Associate Professor, Division of Special Education, School of Education & Clinical Scientist, Biological Sciences Research Center

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The director of the Institute and the investigators were assisted in their efforts by three management groups headed by the coordinator, business office manager, communications director, and data analysis manager. These support personnel are also listed in Table 3-1. Their responsibilities and the overall organization of the Institute are described in Chapter 2 on administrative organization.

CIREEH is deeply indebted to the distinguished and dedicated group of people who comprised its national advisory committee. Committee members included outstanding and nationally known scholars in special education and related fields as well as both local and national consumer representatives. The members of the advisory committee are described in Table 3-2. The activities of the Advisory Committee are described in Chapter 2.

Table 3-2

National Advisory Committee

Name	Discipline or Position	Institute or Location	Areas of Relevant Expertise
Diane Bricker	Director, Preschool Program, Center on Human Development	University of Oregon	Research on, and programs for, young handicapped children
Louis Cooper	Pediatrician, Director of Pediatric Services	Roosevelt Hospital, New York, N.Y.	Pediatrician specializing in multiply handicapped children; pediatrics
Judith Fromm	Parent of Handicapped Child	Fairfield, Conn.	Parental techniques for working with multiply handicapped children.
Howard Garber	Professor	University of Wisconsin	Longitudinal intervention studies with high-risk children
Michael Guralnick	Director, Nisonger Center	Ohio State University	Research on, and programs for, preschool handicapped children
Frances Horowitz	Professor of Psychology	University of Kansas	Research in infant and child development; expertise in formulating research plans and strategies
Sharon Hostler	Pediatrician; Director, Early Childhood Program for the Handicapped	University of Virginia	Programs for multiply handicapped children; pediatrics

Table 3-2
(Continued)

National Advisory Committee

Name	Discipline or Position	Institute or Location	Areas of Relevant Expertise
Merle Karnes	Professor	University of Illinois at Champaign-Urbana	Programs for, and development of, mildly handicapped children
Phyllis Levenstein	Executive Director	Verbal Interaction Project, Freeport, New York	Design and implementation of intervention programs for parents and high risk children
Donald MacMillan	Professor	University of California at Riverside	Intergration of handicapped and nonhandicapped children in educational programs
Saralyn Oberdorfer	Commission Member	Georgia Governor's Commission on Assessment of Young Children	Public policy.
John Rynders	Professor of Special Education	University of Minnesota	Curriculum for multiply handicapped children
Anne Sanford	Outreach Specialist	Public Schools, Chapel Hill, N.C.	Outreach programs; dissemination strategies
Joseph Stevens	Associate Professor	Georgia State University	Research design and methodology; development and evaluation of intervention programs for high risk families

CHAPTER 4

Characteristics of Successful Parents of Moderately/Severely Handicapped Children

James J. Gallagher

Background and Purpose

The increasing trend to educate and raise handicapped children in their own homes and communities, instead of sending them to an institution, has focused greater attention on the role played by family members of the handicapped child. There has been a significant increase in parent/professional interaction, and the parent has become one of the focal points of treatment, with special parent training programs designed by professionals hoping to improve the status of young handicapped children. Turnbull & Turnbull (1978) list several reasons for this apparent increased interest in parents:

1. The experimental evidence that parents can positively influence the development of their children by teaching them at home.
2. The encouraging results of early intervention in ameliorating some of the developmental deficits associated with moderate and severe handicaps.
3. The success of parents in bringing litigation to establish educational rights of their children.
4. Federal legislation, notably Public Law 94-142, that sets forth clear standards for parental involvement in the educational process.

Rationale

It has been well-known from clinical observation that parents can have dramatically different responses to the problem of having a handicapped child. There appear to be two major and separate crises facing the family of the handicapped. First, the symbolic death of the expected normal child that comes when the parents are confronted with the fact of the handicapping condition; and second, the continuing stress that comes with the burdens of daily care of the handicapped (Farber, 1976). Some of the factors that are associated with increased stress are:

- an older child
- fewer support systems available to the family
- severity of the child's physical incapacitation
- degree of the child's caretaking demands

(Bristol, 1979; Cummings, 1976; Lewis, Beavers, Gossett & Phillips, 1976)

One major omission was information about the characteristics of families that have been able to make an effective adjustment to having a handicapped child. Knowledge of those factors related to successful adaptation should provide one useful basis for future parent training activities on the part of the professional.

The present investigation identified highly successful parents of moderate to severely handicapped children and compared them with other parents in order to provide knowledge of the distinctive character of the successful parent adaptation.

Methods

Sample. Subjects in the basic study were fifty pairs of parents of moderately to severely handicapped children who had enrolled their children in a preschool demonstration program for handicapped children. Parents were selected from five HCEEP centers that had volunteered for the study. These centers represented a geographic diversity. They were located in Utah, Georgia, Vermont, and Illinois. Each of the families in the study met the following criteria: (a) two parents present in the home; (b) above poverty level income; (c) handicapped child below the age of five; (d) child enrolled in the HCEEP program for six months or more; and (e) agreement to parent interviews.

Procedure. For those centers that agreed to participate, a rating scale was designed to be filled out by the professional staff on each of the parents. Eight items representing good mental health were arranged on a scale from 1 to 5. An average rating of 4.5 on the 5.0 scale was used to identify successful parents. Those parents who achieved an average score of 3.0 to 4.0 were judged as "average" parents. Scores at the lowest end of the distribution (a score of 1) on any item eliminated the family from consideration. All families who scored between 4.0 and 4.5 were also eliminated from consideration in this study in order to insure a distance between the two groups. A rerating of the cases after a month's absence resulted in 86 percent consistency when the judgment was made by the same staff members; and 70 percent consistency when another staff member rated the same families. In only one case out of twenty did a family move from successful to average in such ratings. The degree of stability appeared satisfactory for the classification of parents into these two groups.

Staff members from the CIREEH project conducted an on-site structured interview based upon an adaptation of the Bronfenbrenner Family Questionnaire, and each parent independently filled out three other scales. The results and analysis of the study were based upon the findings from these instruments.

Instruments. The four measures used in the study were as follows:

1. The Bronfenbrenner Family Questionnaire. This is a structured interview originally designed for families with normal preschool children. It was modified slightly to meet the special needs of families with children with handicapping conditions. The questionnaire covers ten major areas, and the families fill out a quantitative scale rating each of the ten areas after each of those interview segments (Bronfenbrenner, Avgar, & Henderson, 1977).

2. The Holmes and Rahe Schedule of Recent Experiences. This scale, designed as a stress indicator, focuses on life-event changes that have occurred over the past three years. The items on the scale have been weighted for relative stress by consensus judgment, and the weighted sum of checked items was the stress score (Holmes & Rahe, 1967).

3. The Gore Social Support Measures. The scale measures the perceived support that the parent feels from the spouse, friends, and neighbors. This scale was adapted from work with the impact of unemployment on families (Gore, 1973).

4. Gallagher-Cross Family Role Scale. This scale was developed by the project to measure the degree of responsibility taken by the father or the mother in twenty different major family roles. These responsibilities, extracted from the literature on family functioning, ranged from breadwinner to nurse to teacher to moral leader, etc.

   Parents were first asked who takes responsibility for the role of the family, what in their judgment would be the most desirable role pattern in their family, and their degree of satisfaction with how the role is being carried out. Readmission of the scale to a sample of 20 families over time yielded similar patterns. In addition, forty parents were administered a rating scale on degree of spouse participation. Correlations between spouse participation role patterns were statistically significant (Bristol & Gallagher, 1982).

Results

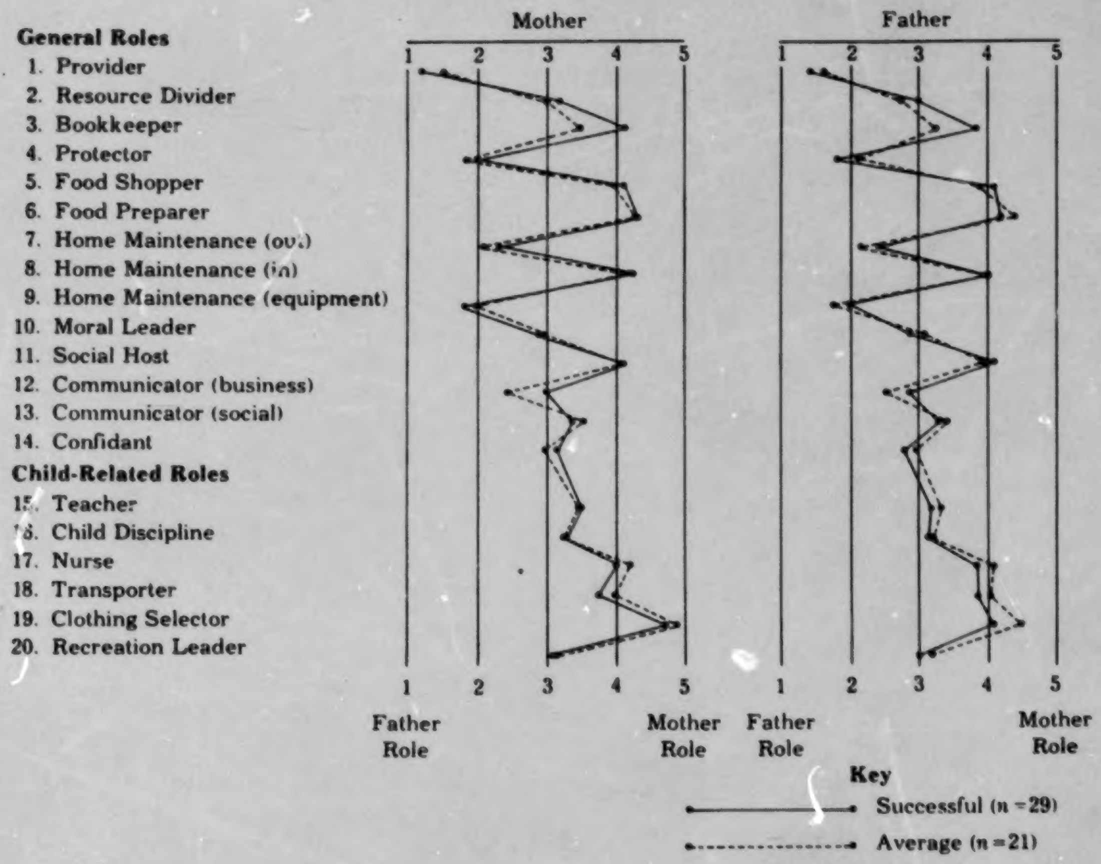
A discriminant analysis of overall group differences on the summary variables of stress, family role, and attitudes was conducted. The interrelationship of the key variables in the study was also calculated. The discriminant analysis yielded no major differences between successful and average families on the global measures of stress and role. In terms of specific life changes identified as related to the handicapped child, all of the successful and average fathers and mothers checked having a new family member and the health of the family member as major causes of life changes. The successful and average mothers tended to note a change in sleeping habits as one of the consequences of having a handicapped child. Fathers checked this item with much less frequency, clearly indicating that it was the mother who carried the responsibility in the family when the handicapped child upsets the nocturnal routines.

In terms of support from spouse, both average and successful families were strong in reporting major spouse help, support, and sympathy in the family, and all the mothers reported a strong feeling of being loved. They were much less positive about support from neighbors as opposed to friends. In the Parent Role Scale (see Figure 4-1), a typical pattern of male-female division of responsibilities was found. In the figure, scores to the low end of the scale represent father responsibility and scores at the high end (5) represent mother responsibility. The father took the major responsibilities as provider, protector, and handler of home maintenance; whereas the mother had major responsibilities as bookkeeper, food-shopper, food preparer, social host, nurse, and clothing selector. Roles mutually shared were teacher, child discipliner, moral leader, and communicator. In both sets of families, all groups agreed that the father should participate more in both general family roles, and specifically in the child care roles.

In comparing the correlations between father and mother measures of stress and role responsibilities, there was a tendency for mothers and fathers of the successful families to agree more closely with each other on perceived stress within the past six months. They also agreed on the current role satisfaction, whereas, in the average family, there was a tendency for disagreement between the mother and the father as to the level of satisfaction in the way family roles were currently being carried out.

Figure 4 - 1

"Successful" and "Average" Wife's and Husband's Ratings of Who Currently Fulfilled 20 Family Roles. (1 = husband's role, 3 = shared role, 5 = wife's role).



Special attention was paid to the role of the fathers of young handicapped children. The traditional father role of physical playmate and model for the male child seems to be largely diminished or not present at all when the child is moderate/severely handicapped The basic question to be answered by professionals is: What responsibilities should take the place of traditional father roles? Is the father to be seen only as a sophisticated babysitter giving the mother occasional respite care, or are there alternative role functions to be played? There was general agreement in both sets of families that the father should be playing a more active role within the family, the mothers feeling this more strongly than the fathers (see Table 4-1).

In a separate analysis, the results on the Bronfenbrenner interview instrument indicated that there were two differences that reached a $p < .05$ level. The "successful" mothers rated themselves more positive on the dimensions of work (those that did work outside the home) and self as parent. On all of the variables in Table 4-2 the successful mothers group rated themselves as higher or more positive by mean scores than the average mothers, but these differences did not reach a $p < .05$ level (Gallagher, Cross & Scharfman, 1981).

A pilot study compared the allocation of responsibilities in families with handicapped children and in those with nonhandicapped children. A sample of fifty parents of handicapped children (the same sample as in the first study) was compared against a sample of eighty three pairs of parents on their performance on the Gallagher-Cross Parent Role Scale. Despite differences in geography and religion in the groups, one of the major findings of the pilot work was the close similarity in the division of parental role responsibilities in two-parent intact families, regardless of whether or not there was a handicapped child present in the family. There was not a reassignment of task responsibilities within the family of handicapped children as would be expected on the basis of the "balance exchange" theory of Kamoravsky (1962). The suggestion in this theory was that the father should take a more active role because of additional pressures on the mother. This did not happen, although the other results of the study make it clear that both mother and father wanted it to happen! They apparently did not know how to bring about the desired change.

Discussion and Recommendations

The results of the present study suggest a more intensive investigation into how to improve the counseling of fathers of preschool handicapped children so that they can participate more effec-

Table 4.1

Comparison of Mean Actual vs. Ideal Roles

Father's Responsibilities

	General Family Roles		Child Roles	
	More	Less	More	Less
Successful Husbands	9	5	6	0
Successful Wives	12	2	6	0
Average Husbands	7	7	6	0
Average Wives	12	2	6	0

Table 4-2

Interview Attitudes

(Bronfenbrenner)

Successful vs Average Mothers

Variable	Successful		Average		P
	mean	σ	mean	σ	
Work	9.40	2.06	5.72	5.02	<.05
Child Care	3.79	2.36	2.47	4.85	.21
Child	4.58	3.99	3.19	3.51	.20
Self as Parent	2.62	2.07	.95	2.67	<.05
Help - Spouse	6.10	1.80	5.60	2.40	.42
Help - Other Adults	6.27	3.00	5.19	2.89	.21
Help - Community Service	9.79	5.29	9.61	6.64	.91
Help - Media	7.96	4.27	6.38	4.43	.21

tively in the family. Since both fathers and mothers agree on the desirability of such action, it appears to be the responsibility of specialists working with preschool handicapped, such as those in the HCEEP programs, to devise a more extensive training program with appropriate training materials to aid in that process.

There is some indication from the pilot work that the presence of a handicapped child does not make major differences in the role functions or desired role behavior on the part of the partner. It appears that more general factors in the family determine the pattern of accepted responsibilities beyond the pressure of a handicapped child. More attention needs to be paid to the overall needs of the family if special educators are to play a useful, supportive role. Exclusive focus should not be placed on the influence on the family of the special needs of the handicapped child. From an ecological standpoint, it is possible that economic pressures or other family stresses quite apart from the handicapped child may make it difficult for the parents to respond adequately to handicapped child's needs. A broader ecological approach to the family and the overall family needs may need to be taken in order to be of maximum help.

Following from these results, it would seem important to compare families with handicapped children and those without handicapped children, but with roughly matching income level and family structure, on the allocation of family responsibilities. The levels of stress and division of responsibilities within the family can be reviewed to see to what extent the young handicapped child forces a modification in family pattern.

A number of observers have suggested that there is a major transition period when the child is taken from a relatively protected preschool setting to the public school environment which may cause a variety of problems. We need to understand the nature of these problems if we are to be of maximum help in counseling and supporting families during this transition phase.

We need to study the special adaptation problems of families with special needs (i.e., one-parent families, families with limited financial sources) to see if these needs modify the problems of adapting to a handicapped child.

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(CIREEH products, cited in this section, are referenced in the Products List in Chapter 13.)

CHAPTER 5

Families at Risk

Background and Purpose

Although we have traditionally considered only child outcomes (usually immediate outcome) as the measure of the success of early intervention, there has been increasing recognition, especially for more severely handicapped young children, that long-term, positive outcomes for the handicapped child also depend on the successful adaptation of the family to the child and the prevention of family crises (Gabel & Kotsch , 1981; Schell, 1981; Foster, Berger, & McLean, 1981; Bristol & Gallagher, 1981).

Problems in adaptation and family crises such as divorce, desertion, and institutionalization in these families have been well documented (Cummings, Bayley, & Rie, 1966; Love, 1973; Reed & Reed, 1965; DeMyer, 1973). There is also evidence, however, than many families adapt successfully to the presence and care of a handicapped child and are functioning well in spite of the increased demands (Bristol, 1979; Grossman, 1972; Burden, 1980). At the present time, however, little is known about the factors that are predictive of stress in these families and few systematic data are available about characteristics, strategies, or beliefs that enable some families to cope successfully with the demands of having a handicapped child.

The purpose of this two-year program of research was to identify characteristics of the child and the family which contribute to both positive and negative adaptation for mothers of handicapped children.

Methods of Procedure

Subjects. Fifty-two mothers of handicapped children were recruited from referrals to the statewide Treatment and Education of Autistic and Related Communications of Handicapped Children (TEACCH) Program. To obtain as representative a sample as possible within the limits of parental consent all consecutive admissions to the program were included in the study (89% of mothers contacted agreed to participate). In order to include the "hard to reach" parent who is a matter of particular concern to early intervention programs, all mothers who agreed to participate were interviewed, including those without telephones (contacts were made through neighbors or social service agencies), and those in remote and relatively inaccessible areas.

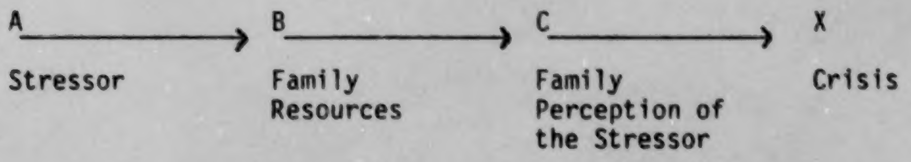
The mean age of the mothers was 31 years (range 19-48). All five Hollingshead's (four factor index) social classses were represented in the group. Mother's educations ranged from junior high level through graduate school with the average response indicating completion of high school. Forty of the mothers were from two-parent families, 12 were single-parents.

Children's mean age was five years with a range of 1-10. (An incorrect age had been listed for the ten-year-old in the referal information and the correct age was not ascertained until all data were collected.) Children's IQ's ranged from 9 to 91 with a mean of 54. All children were living at home, all but two with their biological parents. Thirty-two of the children were autistic, the remainder had communication impairments and most were retarded.

Procedures. Before parents had received services, mothers who agreed to participate in the study were sent packets of self-report measures to complete prior to a scheduled home visit. Home visits were then made to collect the parent self-assessments and to conduct the structured interviews and observer ratings of mother, child, and siblings (when available). In most of the cases the handicapped child was home for all or part of the interview and coping ability could be observed directly. In a few cases, the child was not available at the time of the interview and competence in coping had to be inferred from parental and sibling descriptions of problems and the usual mode of handling them. A follow-up visit was then made approximately 9 months later.

Measures

This research was guided by a conceptual model for family coping with stress first developed by Hill (1949) and subsequently confirmed in over three decades of research in family coping with stresses other than that of having a handicapped child (McCubbin, 1979).



In this model, although the severity of the stress is important, the family's crisis meeting resources and definition of the problem mediate the family's ability to prevent a stressor event from creating some crisis in the family system. Measures of these A, B, and C elements were collected in the proposed study and used as predictors of family crisis (X). A summary of these measures is contained in Table 5-1. Assessment of the severity of the stressor (A) included measures of characteristics of the handicapped child which may impact on the family and measures of general family stress which may exacerbate the negative effect of the child on the family. Family resources (B) included measures of perceived helpfulness of support from family, friends, and service providers as well as active coping strategies used. Family perception of the stressor (C) measured beliefs about having a handicapped child. Outcome measures included indices of marital adjustment, maternal depression, and acceptance and coping with the handicapped child.

Results. The preliminary results presented below are based on data collected at the time of the initial evaluation of the child at TEACCH, before the child or parent has received any intervention services. Nine month follow-up data are presently being collected and will be analyzed when data collection is complete.

One of the objectives of this research was to determine the percentage of mothers of handicapped children experiencing potentially debilitating levels of stress. Two of the outcome measures, the depression (CES-D) scale, and the marital adjustment index provided normative data and cutoff scores which have distinguished normal from clinical populations in previous studies.

Marital data reveals that 13% of the total group of mothers are separated or divorced and another 18% were never married. Of those who remain married (N=40) 80% have marital adjustment scores at or above the 100 cutoff recommended by Locke-Wallace as indicating adequate adjustment ($x = 112.5$, $\sigma = 23.6$). The majority of these young families, then, who remain married appear to be happily married.

The 13% divorce or separation rate does not appear to be higher than that for this region in general although it was not possible to obtain comparable normative data for families with children these ages.

Thirty percent, however, of the mothers reported CES-Depression scores at or above the clinical cutoff of 36 (scale scored 1-6 vs Radloff's original scores of 0-5). The mean scores for married ($x = 32.8$, $\sigma = 10.8$) and single mothers ($x = 35$, $\sigma = 11.8$) did not differ. Although the majority of both groups were below clinical cutoffs, mean scores for both groups were relatively high. Scores on the depression scale were related to social class with higher depression

Table 5-1

INDEPENDENT AND DEPENDENT MEASURES OF FAMILY COPING WITH STRESS (ABC→X MODEL)

A. STRESSOR

Measure	Purpose
Standardized IQ test (choice of test determined by developmental level of child)	To provide a measure of child intelligence as one dimension of of the severity of child's handicap
Vineland Social Maturity Scale (SQ)	To provide a measure of child's dependency
Holroyd QRS Scales	
Physical Incapacitation Social Obtrusiveness Difficult Personality Characteristics Limits on Family Opportunity	To provide maternal ratings of child characteristics thought to be related to stress
Child Age and Sex	
Modified Holmes and Rahe (1967) Schedule of Recent Experiences (Total weighted score)	To assess the level of general family stress in addition to that caused by the child

B. FAMILY RESOURCES

Measure	Purpose
Coping Health Inventory for Parents (CHIP). (McCubbin et al., 1979; Nevin & McCubbin, in press) (Factors I, II, III)	To assess contribution of active coping strategies to family outcome (I: Family Maintenance; II: Social Support / self esteem ; III: Community Consultation and Information Seeking)
Supports for Parents of Special Children (SPSC) (Informal Support/Formal Support) (Bristol, 1981)	To assess maternal perception of helpfulness of informal and formal supports

C. FAMILY PERCEPTION OF STRESSOR

Measure	Purpose
Definition Scale (Factors I, II, III) (Bristol, 1981)	To assess maternal beliefs regarding having a handicapped child (I: Meaning, II: Guilt, III: Catastrophe)

X. CRISIS

Measure	Purpose
Marital Adjustment Index (weighted total score) (Locke-Wallace, 1959)	To assess normative significance of marital adjustment
Community Epidemological Survey Depression Scale (total score) (CES-D, Radloff, 1979)	To assess normative significance of depressive symptoms in previous week
Home Quality Rating* Scale, Factor I (Nihira, Meyers and Mink, 1980)	To assess family acceptance and coping with the handicapped child

*Observer rating completed after 1½ - 2 hr. About Your Child (Nihira, Meyers & Mink, 1980) Interview scores associated with lower social class standing (Hollingshead 1 = higher class, 5 = lowest).

No normative data are available regarding acceptance and coping and no differences were found between married women ($x = 25.4$, $\sigma = 3.9$) and single parents ($x = 22.07$, $\sigma = 4.7$) on this measure. This score was not related to socioeconomic status.

In a related pilot study (Bristol & Gallagher, reference note 1) it was found that single parents did not differ in perceived helpfulness of formal services ($x = 18.2$, $\sigma = 12.0$) from married women ($x = 15.8$, $\sigma = 7.3$). but did differ significantly in perceived helpfulness of informal social support ($x = 7.0$, $\sigma = 5.4$ single parents; $x = 13.0$, $\sigma = 4.6$ two-parent married mothers). That study also revealed significant differences between the two groups on assistance with child care and household tasks (single parents, $x = 32.7$, $\sigma = 9.2$; married women, $x = 52.7$, $\sigma = 7.4$)

The relationships of specific child characteristics to the criterion measures are shown in Table 5-2. As shown in Table 5-2, the observer rating of acceptance and coping is significantly related to both child's age and the social obtrusiveness of the child. Both relationships are positive, indicating that parents are more accepting of children in the upper end of the restricted age range (1-10) studied and are more accepting of the more obviously handicapped children. The element of clarity of handicap also appears to influence marital adjustment with children who are more obviously retarded (IQ and social quotient or degree of dependency) having a less negative effect on the marriage than those young children for whom the handicap is less clear. This same obviousness of handicap also appears to affect maternal depression with mothers of children who are less socially obtrusive (less obviously atypical in public) reporting more depressive symptoms. A somewhat surprising finding is the inverse relationship between limits on family opportunity and depression. While these children are in this preschool stage, it appears that "sacrifices" the family has made in terms of passing up educational or employment opportunities for the sake of the child have a positive effect on the mother's feelings of depression, perhaps in keeping with the generally religious orientation of most of the subjects in this particular North Carolina population or by making the mother feel she has "done something" for the child's benefit, thereby alleviating feelings of helplessness which Seligman (1975) indicates may cause depression. Some child characteristics, then, are significantly related to maternal depression, marital adjustment, and acceptance and coping with the handicapped child. Knowing about the characteristics of the child does help predict positive or negative family outcomes.

Table 5-2

CORRELATIONS OF CHILD CHARACTERISTICS WITH OUTCOME MEASURES

	Acceptance & Coping N = 52	Marital Adjustment N = 40	Depression N = 52
IQ (N=45)	-.24	-.40*	.09
SQ (N=40)	-.11	-.36*	-.09
KIDAGE	.27*	.10	.03
KIDSEX	.14	.33*	-.007
Physical Incapacitation	-.05	-.07	.14
Social Obtrusiveness	.28*	.04	-.33*
Difficult Personality Char.	-.14	.19	.03
Limits of Family Opportunity	.05	.18	-.28*

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*$p \leq .05$

However, although child characteristics are related to stress and coping in these families, positive or negative outcomes are more strongly related to family resources and maternal beliefs about the child's handicap (See Table 5-3). Mothers who employ coping strategies which involved maintaining self esteem, psychological stability, and drawing on a social support network report fewer depressive symptoms than mothers who do not.

Both family resources and maternal beliefs are also clearly related to marital adjustment in these families. Mothers who express feelings of guilt regarding the child's handicap (endorsing statements which imply that the child has a handicap because of their incompetence as parents or as a punishment for something someone in the family has done), report significantly less marital happiness than those disagreeing with such beliefs. Again, the importance of social support is indicated by the rather strong relationships between perceived adequacy of the mother's overall informal support network in general (spouse, extended family, friends, and other parents of handicapped children) and, in particular, support from fathers regarding the handicapped child.

Most striking of all, are the relationships among family resources and maternal beliefs and the observer ratings of acceptance and coping with the handicapped child. In any study of families of autistic children, one major concern is whether the family will be able and willing to maintain the children in their own homes, at least until the children have acquired sufficient skills to live independently or semi-independently in the community. A direct measure of rate of institutionalization of children in this preschool age range, however, would be relatively meaningless since most institutionalization of these children occurs after this age span. An approximation of the child's prospects for remaining in the home, however, may be the degree to which he or she is accepted by the various family members and the parent's (in this case) the mother's ability to cope with the problems such a child presents. The home observer ratings of the family's acceptance and coping are significantly related to perceived adequacy of informal supports (especially paternal support), the coping strategies used, and the beliefs the mother holds regarding her handicapped child. Mothers who perceive the child's father, relatives, and friends including other parents of handicapped children as supportive of the mother's role as the parent of a handicapped child, have higher observer ratings of family acceptance and coping with the handicapped child. Similarly, all three types of coping strategies, maintaining family integration, cooperation, and an optimistic definition of the situation; maintaining self esteem and informal social support; and interacting with members of the community in seeking information,

Table 5-3

CORRELATIONS OF FAMILY RESOURCES AND BELIEFS WITH OUTCOME MEASURES

Family Resources	Acceptance & Coping N=56	Marital Adjustment N=40	Depression N= 55
Support from Spouse (N=40)	.55***	.56***	-.09
Informal Supports	.42***	.50***	-.25
Formal Supports	.10	.09	-.08
Coping 1,			
Int. Coop. Optimism	.61****	.28	-.18
Coping 2,			
Soc supp. Self esteem	.56****	.26	-.31*
Coping 3,			
Communic & Consult	.49***	.25	-.09
Beliefs			
Meaning	.27*	.22	.05
Guilt	-.42***	-.41**	.21
Catastrophe	-.59****	-.23	.14

*p $\leq$ .05
**p $\leq$ .01
***p $\leq$ .001
****p $\leq$ .0001

services, and carrying out prescribed activities are positively related to acceptance and coping.

Furthermore, the mother's subjective beliefs about the child's handicap are also related to acceptance and coping at this point in time. Mothers who view the child's handicap as an opportunity to learn new skills or as giving meaning and purpose to their lives are more accepting of the child and cope better than those who do not. More clearly, however, parents who express guilt regarding the child's having a handicap or who see it as a catastrophe (e.g., "This is the worst possible thing that could happen to our family.") are rated as having greater difficulty with acceptance and coping.

One of the major objectives of this research was to identify data to be collected from mothers at the time of first program contact which would identify family stress when clinical measures were not appropriate or home observation measures were not feasible because of time or economic constraints. The question raised, then, by the above findings is which of the many measures would best predict each of the outcomes of interest.

Among the problems of analyzing large data sets on a relatively small number (N=52) of subjects is both the problem of capitalizing on chance if the investigators simply generated prediction equations until they find some significant predictors. To mitigate this problem, the investigator limited her analyses by first conducting omnibus tests of the significance of the overall model and only if significance was found for the overall model, then proceeding to look within the model for more specific relationships.

The first analysis, then, consisted of an omnibus test of the relationship of the overall model (A--B--C---X) to determine if, in fact, child characteristics, family resources, and maternal beliefs were significantly related to the outcome measures of maternal depression, and an observer rating of acceptance and coping with the handicapped child. (Marital adjustment was examined separately because inclusion in this omnibus test would have eliminated all single parent families from the analyses). The variables included in the analysis are those listed in Table 1 (A, B, & C predictors; x, the criteria).

The overall canonical correlation of predictor variables with the criteria was .80 which, when adjusted downward for the large number of variables in relationship to subjects, yields a canonical correlation of .71 (F = 1.92, p = .02) indicating a significant relationship between predictors and criteria in the model.

At this point in the analysis, it was not clear whether the model significantly predicted both of the criteria or only strongly predicted either depression or acceptance and coping with the child. Results of omnibus regression tests of the same variables included in the canonical correlation reveal that child characteristics, family resources, and subjective beliefs significantly predict observer ratings of acceptance and coping ($F = 2.91$, $p \leq .01$) accounting for 41% of the variance when the original R^2 is adjusted downward for ratio of variables to subjects. The omnibus regression test for depression was not significant ($F = 1.64$, $p = .12$).

A separate regression with marital adjustment as the criterion variable and the same predictor variables for two-parent families indicates that child characteristics, family resources, and maternal beliefs significantly ($F = 3.97$, $p \leq .01$) predict marital adjustment, accounting for 58% of the variance when adjusted downward for subject/variable rates .

If the overall regression tests were significant, Backward stepwise multiple regression equations were generated to identify these best predictors. (Because of the limited number of subjects, not all variables but only the most likely predictors were included in the equations).

A backward, stepwise multiple regression equation including child's sex, degree of dependency, informal social support, support from spouse, and maternal guilt significantly ($p < .01$) predicted marital adjustment accounting for 45% of the total variance. The best predictors, informal support regarding the handicapped child and guilt, accounted for 37% of the variance. The knowledge of other family stresses added to the prediction bringing the total variance accounted for to 55%. ($N = 32$ because of incomplete SQ or family stress data on some subjects. Total two-parent families = 40.)

Finally, acceptance and coping can be most parsimoniously predicted by the child's age, IQ, and degree of dependency, by the perceived adequacy of the mother's informal support network, and her use of coping strategies which involve interacting with members of the community in seeking information, services, and carrying out prescribed activities. Knowledge of other family stresses adds 5% to the prediction bringing the total variance accounted for to 63%.

Use of an alternative data analysis strategy using data reduction techniques and resulting summary or factor scores as predictors or criteria is presently being explored. Additional subanalyses are also planned for comparisons of handicapped groups and to explore relationships of maternal employment, race and other demographic variables to outcomes.

Discussion and Recommendations

The results of this study indicate that the majority of these mothers are coping well, although a significant number of both married women and single parents may be experiencing potentially debilitating levels of depression. The percent of mothers affected in this study is comparable to that found by DeMyer (1979) for a similar population. Whether such depression is alleviated simply by providing early intervention services for the child and parent training for the mothers will be assessed in the analysis of the follow-up data presently being collected. If it is not, it may be important to train early intervention staff to recognize the symptoms of such depression and to refer mothers for appropriate treatment.

As in previous studies (Farber, 1959; Bristol, 1979), boys appear to have a more adverse effect on families than girls. The lack of age effects on depression and marital adjustment is also consistent with previous findings for young families. Increasing age was, however, associated with improved maternal acceptance and coping, a finding similar to that of Miller and Kaplan (1982). It appears that age effects may be curvilinear with increased age associated with better family functioning until mid-adolescence. Negative effects for age appear to be found only in studies that include late adolescents (Farber, 1959; Bristol, 1979). Such differences should raise cautions about the generalizability of findings from one child age or stage of family development to another. For example, in the present study, sacrifices the family has made during these preschool years appear to relieve depression. Continued sacrifices of family opportunity over time, however, would be expected to have long term negative effects on the family. Results of assessing this variable in families of adolescents would be expected to yield markedly different results.

The fact that positive or negative outcomes for these mothers were more strongly related to family resources and beliefs than to severity of the child's handicap confirm the applicability of Hill's (1949) classic model of family coping with stress to families of handicapped children and provides a basis for optimism regarding the home care of severely handicapped children.

The study also makes clear that mothers respond not only to the objective reality of the child's handicap, but to their subjective perception of that reality. The contribution of maternal guilt to depression, marital problems, and acceptance and coping, emphasizes the need to assess such subjective perceptions, especially in families from different cultural groups whose belief systems may be different from the service provider's. The fact that obviousness of the handicap was related to lower stress also indicates the need for early identification of the child's handicap and early parent education to minimize disagreements or self-blame regarding the child.

The number of single parents found among these consecutive program referrals and the percent of these mothers employed outside the home (50%) indicate that assumptions about traditional family structures and functions are no longer tenable. Research and service delivery systems should address the unique needs of these changing families.

Finally, the importance of perceived adequacy of informal social support, especially from fathers, in predicting successful outcomes for these mothers emphasizes the need to identify the specific kinds of paternal support that contribute to successful child and family outcome and the extra-familial sources of support which may also be critical, especially in single-parent families. Wahler's (1980) work suggests the importance of type and level of such informal support in maintaining the hard-won gains of parent training.

These correlational data, of course, can only suggest, but do not demonstrate cause and effect relationships, and caution must be exercised in interpreting the findings. Another limitation of the study is the use of maternal self-report data which may be subject to deliberate distortion or errors of recall. This is a valid concern mitigated only partially by the use of home observer ratings. It appears, however, from the results of the study that it is precisely this subjective maternal perception rather than the objective reality of the child's handicap that may be related to acceptance and maintenance of the child in the home.

It is not clear to what extent the results of this study are generalizable to other geographic areas or other types of handicapping conditions, nor if results found will be replicated in the follow-up data on these same families. It is clear that there is much to be learned regarding successful family adaptation to the handicapped child, and the relationship of such adaptation to the subsequent learning and adjustment of handicapped children.

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CHAPTER 6

Family Networks and the Development of Adaptive Behavior

Earl S. Schaefer

Background and Purpose

The major purpose of the project was to study the family environment and the family relationships that influence the competence and adjustment of the handicapped child, and the quality of life of family members. Two-parent families of handicapped and normal young children and their older normal school-age siblings were studied to determine the significance of the father, the mother, and the marital relationship to the adjustment and competence of the children and the quality of life of family members.

Three major objectives were: 1) to determine the correlations of maternal and paternal educational and childrearing attitudes, beliefs, values and behaviors with the intellectual development of the handicapped child and normal sibling. 2) To determine the correlations of husband-wife relationships and sibling relationships with child socio-emotional adjustment. 3) To determine how family relationships, socio-economic status, and the presence and extent of handicap are related to the quality of life of mother, father, handicapped child, and normal sibling.

The major activities of the project were conceptualization, measurement, and research on family environments, family relationships, and child physical, intellectual, and social-emotional functioning at home and school. A major first year project was development, data collection, and analysis of reliability and factor structure of a version of the Classroom Behavior Inventory for use in day care or preschool with children between two and six years of age. Additional methods for data collection from teachers and parents were developed for the second year study of normal and handicapped preschool children and their families. Methods and findings of the earlier studies contributed to the final study of a sample of two-parent families with normal or handicapped young children and older normal elementary school age siblings.

Rationale

The project was motivated by an analysis of the scope and focus of research relevant to early intervention. It was concluded that research should move from a narrow focus on the individual child or on the mother-child relationship to a study of the network of family relationships including father-child and father-mother relationships (Schaefer, 1976). Although the mother is still the major focus in both research and intervention, attention to the role of the father in child care and child development is increasing rapidly (Lamb, 1976, 1978; Biller, 1974). Radin (1973) and Epstein and Radin (1975) have shown correlations among observations of paternal behavior, child motivation in the testing situation, and mental test scores. Clinical studies suggest that father-son relationships as well as the mother-son relationships are related to delinquency (Andry, 1960, Rutter, 1971). Rode (1971) has shown that adolescent alienation is related to the adolescent's perception of both mother and father.

Parallel to the increase in attention to the role of the father in child development has been an increase in attention to correlations of father-mother relationships with child adjustment. Nye (1957) reported that children from unhappy, unbroken homes are more maladjusted than children from broken homes. Robins (1966), Roff (1971) and Rutter (1971) have found that the husband-wife relationship is correlated with the antisocial behavior of boys. Reports on the Locke-Wallace Marital Adjustment Test (1959) by mothers and fathers are substantially intercorrelated, and both reports are related to the adjustment of school age boys (Danjczek, 1971; Johnson & Lobitz, 1974). Marital adjustment has been related primarily to conduct-problems and deliquency of boys. A longitudinal study of the impact of divorce on family functioning and child development also showed that variations in the mother-father relationship were related to variations in adjustment of the child (Hetherington, Cox, & Cox, 1978). Frequent visitation was related to disruptions in the child's behavior if the parents disagreed in their attitudes toward the child or were engaged in conflict.

Previous research on father-child relationships and mother-father relationships suggests that research on family relationships of handicapped children will contribute to the description of family variables that influence the child's adaptation.

Not only the handicapped child, but also the entire family of the handicapped child may be vulnerable during the process of development. Earlier findings that stresses of childrearing may influence the husband-wife relationship (Rollins & Feldman, 1970) support findings that the stress of rearing a handicapped child has an impact on the husband-wife relationship (Howard, 1978). The presence of a handicapped child in the family may also have an impact on the family relationships and development of siblings. Variations in family relationships and in strengths, skills, supports, and stresses may influence both the family's ability to provide care and foster development of the handicapped child and to maintain the quality of life of other family members. Research on correlates of the quality of life of the family as perceived by the mother and father of the handicapped child may contribute to improved evaluations of families and to the development of services designed to meet identified family needs.

The need to study child adaptation both in the family and in school is supported by a review of several studies that find relatively low correlations between parents and teachers in their descriptions of the social adjustment of children (Schaefer, 1981). Studies of similarities and differences in the adjustment and competence of siblings are needed to test the hypothesis that family correlates of adaptation of the young handicapped child can be generalized to the older normal sibling.

Methods

First year. During the first year of the project, the Preschool Version of the Classroom Behavior Inventory was developed and tested with a sample of 98 preschool children between two and six years of age (Schaefer & Edgerton, 1980). This inventory was used during the remainder of this study and has contributed significantly to research by other investigators.

Second year. Additional inventories were developed or adapted for use by parents and teachers from analyses of data collected in previous projects by the investigator. The sample for the second year included 18 families with handicapped preschool children and non-handicapped older siblings and a comparison group of 18 families with two non-handicapped children. In all families the younger child was enrolled in a preschool program. Nine of the handicapped children were mainstreamed and the other nine attended special classes for the handicapped.

Both mothers and fathers completed extensive inventories about their children, family relationships, and their values, attitudes, and practices in regard to childrearing. Teachers provided ratings of adjustment and competence of both the preschool children and their older siblings, and of parental involvement in the children's education. Data was used to evaluate the nine new or adapted inventories and to provide hypotheses to be replicated in the following year.

Third year. The final sample that was recruited by family consultants of the North Carolina Developmental Evaluation Clinics was composed of 39 intact families including a 3-to 8-year-old child with a biomedical handicap and an older non-handicapped sibling. A comparison sample of 18 intact families with two non-handicapped children was recruited from public schools.

Four inventories that had been developed in the first and second years were used without revision in the third year study. In addition five inventories were revised on the basis of second year data, and one new inventory was developed in the third year. Following the completion of the third year, a measure of modernity in childrearing was developed from data obtained in this study and in two other samples (Schaefer & Edgerton, 1981a). Instruments that were developed or revised during the study are listed in Table 6-1.

Cantril's (1965) ladder scale on the quality of life, anticipated future life, and life of spouse and children was completed by mothers and fathers during the third year interviews. The Locke-Wallace (1959) Marital Adjustment Scale (MAS) and the Marital Autonomy and Relatedness Inventory that was developed in this project provided data on marital relationships.

Results

Conceptualization and measurement of child adaptation. The goals of conceptualization, measurement, and development of conceptual models for research on the network of family relationships and on the child adaptation at home and in school were successfully achieved. Among the major products are reliable and valid instruments for the study of family relationships and child adaptation at home and at school. The Preschool Version of the Classroom Behavior Inventory, developed in the first year, includes 11 scales: Verbal Intelligence, Creativity/Curiosity, Task Orientation, Considerateness, Extroversion, Independence, Distractibility, Apathy, Hostility, Introversion and Dependence--that describe positive and negative poles of major areas of intellectual competence, motivation, and social and emotional adjustment.

The Social Assets Inventory, developed during the second year of the project, yielded additional dimensions of child adaptation from reports by parents and teachers. Relatively high agreement among mother, father and teacher on descriptions of expressive talent or mental ability and athletic ability or physical coordination, and a good differentiation of handicapped and non-handicapped children from data on these scales suggests that the Social Assets Inventory might be useful in community screening for handicapped children and in involving parents in diagnostic evaluations. Analyses of a Teacher Report of Child Behavior toward the Teacher also yielded clear dimensions that describe social and emotional adjustment of the child in the classroom.

Table 6-1

Assessment Methods Developed or Revised During the Project

Methods and Scales	Number of items	Informant
1. *Classroom Behavior Inventory--Preschool Version.* Verbal Intelligence, Curiosity/Creativity, Apathy, Extraversion, Introversion, Independence, Dependence, Task-Orientation, Distractibility, Considerateness, Hostility.	60	Teacher
2. *Social Assets Inventory.* Expressive Talent, Athletic Ability, Appearance, Health, Relationship to Adults	20	Teacher/ Parent
3. *Bipolar Trait Ratings.* Intelligence, Extraversion, Task-Orientation, Considerateness	16	Teacher/ Parent
4. *Teacher Report of Child Behavior toward the Parent.* Resisting Control, Obedience, Positive Behavior, Detachment, Independence	39	Teacher
5. *Parent Report of Child Behavior toward the Parent.* Resisting Control, Obedience, Positive Behavior, Detachment, Independence	25	Parent
6. *Teacher Report of Parent Involvement.* Parent-teacher Collaboration, Parent as Teacher, Demanding, Evasive/Defensive	20	Teacher

Table 6-1 (continued)

Methods and Scales	Number of items	Informant
7. Parent Report of Parent-Teacher-child Interaction. Conference Helpful, Free to Contact Teacher, Teacher Open to Suggestions, Uncomfortable with Teacher, Teacher Expects too Much, Feels Blamed by Teacher, Child Likes School, Child is Learning, Child Needs more Attention	27	Parent
8. Parent as Educator Interview. Self-reports of Parent Behavior, Parent Roles in Education, Childrearing and Educational Beliefs, Values for Children	84	Parent
9. Parental Modernity Scale. Progressive Hemocratic Beliefs, Traditional Authoritarian Beliefs	30	Parent
10. Marital Autonomy and Relatedness Inventory. Love, Detachment/Rejection, Control, Autonomy/Respect, Independence vs. Dependence, Agreement vs. Disagreement on Childrearing	74	Husband/ Wife
11. Sibling Inventory of Behavior. Empathy, Leadership, Kindness, Acceptance, Avoidance, Unkindness, Anger, Embarrassment	28	Parent

A combined factor analysis of the scales from the Classroom Behavior Inventory, Social Assets Inventory, and Teacher Report of Child Behavior toward the Teacher yielded three major dimensions: 1) Academic competence with highest loadings on intelligence, independence, task orientation, and expressive talent, 2) Socialization with highest loadings on considerateness and responsibility versus hostility and protest, 3) Extraversion with highest loadings on extraversion and friendliness to teacher versus withdrawal and introversion. These three dimensions of social and emotional adjustment and academic competence provide a parsimonious integration of data on child adaptation in the classroom.

Both mother and father described the child's adaptive behavior in the home with the Social Assets Inventory, with a Parent's Report of Child Behavior to the Parent Inventory, and with Bipolar Trait Ratings. A factor analysis of intercorrelations of scales from these methods clearly replicated dimensions of competence, socialization, and extraversion that had been isolated from teacher reports. Cost effective methods for measuring these major dimensions of child adaptation at home and at school should contribute to further research in these areas.

Findings on child adaptation. Intercorrelations among descriptions by mother, father, and teacher showed relatively high agreement on competence; relatively good agreement between mother and father, but low agreement of parents with teachers on socialization; and significant correlations among mother, father, and teacher on extraversion. Correlations between younger siblings, half of whom were handicapped and half normal, and older normal siblings showed substantial correlations between siblings on competence that were similar to expected correlations between siblings' intelligence test scores. However correlations between siblings on socialization and extraversion tended to be low and nonsignificant.

The findings of low correlations between adjustment at home and at school and low sibling similarity on social and emotional adjustment suggest that factors that influence emotional adjustment may differ across settings and for different children from the same family. Similarities between siblings and across settings in academic competence suggests that family variables correlate more consistently with academic competence than with social and emotional adjustment.

Although handicapped children were seen as less competent by parents and teachers, biomedical handicaps were not significantly related to socialization and extraversion in this sample.

Relationships between handicapped children and older siblings. Older brothers and sisters were reported by parents to be kinder and less competitive with handicapped than with non-handicapped younger siblings. Small but significant differences were found on nine of twelve scales, all in the direction of a more positive relationship between the two children if one was handicapped. Compared with older brothers and sisters of normal children, the older siblings of handicapped children were described as more likely to help, to comfort, to overlook the handicap or age difference, to assume responsibility, and to be pleased with progress made by the younger child. They were less likely to show anger or jealousy, to avoid contact, and to hurt the younger child's feelings.

Further analyses showed that impaired intellectual competence, rather than physical handicaps, seemed to be related to the group differences in sibling behavior. The older child's anger, jealousy, and tendency to tease were positively correlated with the younger child's level of mental ability. Perhaps the more intelligent the younger child is, the more he or she is seen as a rival by the older child. Age difference between the two children was not significantly correlated with the older child's behavior toward the younger, except that there was more contact between children closer in age.

Parent variables that relate to child outcomes. Data on parental education attitudes, beliefs, values, and behaviors from the Parent as Educator Interview and parent socioeconomic status variables of maternal and paternal education and occupation were significantly correlated with academic competence, replicating findings from several previous samples. More specifically, children were likely to be rated by their teachers as more intelligent and motivated toward achievement if the parents reported that they do the following:

1. Talk to the children about subjects outside their daily experience.

2. Share activities with the child.

3. Place less emphasis on conforming values (cleanliness, neatness, politeness, and good manners) and more emphasis on social values (kindness) and self directing values (imagination, independent thinking, curiosity).

4. Encourage imagination, playfulness, and free expression of ideas.

5. See their role in the child's schooling more as listening, encouraging and enriching, and less as helping with homework and discipline.

For preschool children, half of whom were handicapped, shared conversation and activities were most highly correlated to the child's ratings on intelligence. For school-aged children each of the above parent characteristics were strongly correlated, and at higher levels. The attitudes and practices of fathers were somewhat more highly correlated with child competence than the same characteristics of mothers, confirming the importance of including fathers in research and intervention.

Factors and correlates of marital adjustment. A factor analysis of a Marital Autonomy and Relatedness Inventory (MARI) replicated two major dimensions of perceived behavior of the spouse that were identified in the pilot study. The dimension of Autonomy versus Control was best defined at the positive pole by agreement that the spouse "Gives me as much freedom as I want" and "Lets me do anything I like" and at the negative pole by "Expects me to do everything his/her way" and "Wants to have the last word on how we spend our time." The factor of Relatedness versus Hostile Detachment was best defined at the positive pole by "Shares in planning family activities" and "Talks over problems with me" and at the negative pole by "Acts as though I'm in the way" and "Makes fun of me."

On the Locke-Wallace Marital Adjustment Scale a factor of Value Consensus was best defined by agreement on conventionality and agreement on philosophy of life. A factor of Marital Satisfaction was best defined by an estimate of happiness in the present marriage and agreement that if they had to live life over, they would marry the same person.

There were substantial correlations between mother and father scores on the Locke-Wallace MAS and on the Marital Autonomy and Relatedness Inventory, and substantial correlations between scales from the two methods. Parents' reports of marital adjustment were significantly correlated with their reports of the older child's socialization in the home but nonsignificantly correlated with teacher reports of child socialization in the classroom. Reports of marital adjustment were also correlated with parent reports of the older sibling's positive behavior toward the younger sibling. More positive behavior of older siblings was reported toward handicapped siblings and toward siblings with lower competence than toward nonhandicapped siblings. These analyses suggest that positive relationships between mother and father, characteristics of the older child, and characteristics of the younger child are all related to sibling relationships. Significant correlations of marital adjustment with extraverted behavior in the classroom suggest that security in family relationships may lead to expressive behavior in the classroom.

Quality of life. During the third year this research was extended to determine how the network of family relationships was related to the quality of life of family members as perceived by the parents. Correlations of ratings of quality of life with descriptions of marital relationships were high, especially for wives. Anticipated future quality of life was correlated more with wives' than with husbands' reports of marital relationships for wives than for husbands. The factors of marital consensus and relatedness were significantly correlated with the parents' estimate of quality of life of both children, but the factors of marital satisfaction and autonomy were less correlated with the children's quality of life. Correlations of quality of life with marital relationships were far higher than with socioeconomic status or with child characteristics, including the presence and severity of the younger child's handicap. No evidence was found that the presence of a handicapped child was damaging to the family relationships or current quality of life within the groups studied. However when two-parent families were being recruited for the study, it appeared that the divorce rate might be higher among families with handicapped children.

The findings on the importance of marital adjustment to quality of life and to child socialization provide a rationale for development of family services that would support positive family relationships.

Parents' possible contribution to screening for handicaps. The consistent findings of high correlations between parents and teachers on variables that define the child's competence--intelligence, expressive talent, task-orientation, and physical coordination--and the substantial correlations of these variables with a diagnosis of a handicapping condition suggest that parents as well as teachers might contribute significantly to developmental screening (Schaefer & Edgerton, 1981b). The methods used in this study require parent and teacher judgments of the child as compared to other children in an age cohort.

Scales of The Bipolar Trait Ratings and the Social Assets Inventory that can be completed in less than five minutes might be useful in implementation of the Child Find provisions of PL 94-142 or in parent and teacher involvement in developmental screening in the EPSDT program. Since valid ratings were obtained from mother, father, and teacher in this study, each of these informants might provide data that would contribute to identification of children in need of developmental services. Although it was possible to develop cutoff scores for the scales of expressive talent and athletic ability of the Social Assets Inventory that differentiated severely and moderately handicapped from normal children, variability within both diagnosed and undiagnosed children suggested that it is more useful to recognize a continuum of degrees of handicap as well as different types of handicap. It is also possible to differentiate physical and motor handicaps that can be identified by ratings of athletic ability, from cognitive handicaps that can be identifed by ratings of expressive talent and intelligence. The findings show that parents can report that the child is not making developmental gains that are typical for an age cohort without reporting specific developmental achievements. This evidence that parents might contribute to screening, combined with other findings that parents can contribute significantly to diagnosis and treatment of the developmental disorders of their children (Reichler & Schopler, 1976), supports the need for more parent-centered approaches to the delivery of health services to children. Caretakers and teachers might also contribute to screening of children enrolled in child care or education programs.

Discussion and Recommendations

A major finding of the study is the validity of teacher and of parent ratings in evaluating the physical, social, emotional, and intellectual development of the child. The preschool version of the Classroom Behavior Inventory provides reliable and valid data on preschool children that is comparable to data collected during the elementary school years. The several methods for collecting data from parents provide data on the child's adaptive behavior in the home that complements teacher data on the child's adaptive behavior at school. Validity of parent and teacher data in differentiating handicapped from nonhandicapped preschool children suggests that parent as well as teacher ratings might be used in cost-effective screening and evaluation programs.

Correlations of mother and father beliefs, values, and behavior with the intellectual development of both the preschool handicapped child and the older normal sibling suggest that both mothers and fathers should be involved in early intervention with handicapped children. Success of early intervention might be evaluated by determining changes in parent beliefs and behaviors as well as by determining changes in child development. More prospective longitudinal studies are needed on family educational environment, and more research is needed on family centered interventions that have a goal of promoting parent beliefs, values and behavior that contribute to the development of handicapped children.

Marital relationships of consensus, relatedness, marital satisfaction and perceived autonomy are correlated with quality of life of parents, handicapped children, and their siblings. Programs for handicapped children and their families might have a goal of contributing to positive marital relationships and to mother and father collaboration in care of the handicapped child. That goal would complement a goal of involvement of the father as well as the mother of the handicapped child in evaluation and remediation. Evaluation of program success in fostering positive marital relationships and in involving both mothers and fathers in the care and education of the handicapped child would be facilitated by the methods developed in this research program.

The findings on relationships among mother, father, handicapped or normal younger child, and older sibling contribute to a total family approach in research and services. Data on child and family functioning collected from teachers and family members provide a comprehensive view of family functioning and of child adaptation that may contribute to planning for family services, to diagnostic assessment of child and family, to longitudinal research on stability of family functioning and child adaptation, and to improved evaluations of services for children and their families.

The project provides evidence of the validity of an ecological, developmental perspective that focuses on the role of parents in fostering the development of handicapped children. Research that is designed to develop this approach would contribute to the adaptive behavior and quality of life of handicapped children and their families.

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(CIREEH products, cited in this section, are referenced in the Products List in Chapter 13.)

CHAPTER 7

Parent Involvement for Programs of Handicapped Children

Ronald Wiegerink, Anne Hocutt, Paula Beckman-Bell,
Peggy A. Ogle, & Rebecca Posante

Background and Purpose

The rationale for parent involvement in early education programs has traditionally focused on improved outcomes for children and has been based on a belief in the malleability of intelligence and the importance of parents in providing early stimulation in order to improve children's cognitive processes and skills (Wiegerink, Hocutt, Posante, & Bristol, 1980). Other rationales have included assistance for parents through increased emotional supports, improved child-raising skills, increased satisfaction, and fulfillment of their right to be involved. Because of these reasons, parent involvement is an important component of most Handicapped Children's Early Education Projects (HCEEP) and is increasingly being considered an important element in any successful preschool program (Bronfenbrenner, 1972; Goodson & Hess, 1975; Wiegerink, Hocutt, Posante, & Bristol, 1980; Wiegerink & Parrish, 1978).

The CIREEH Parent Involvement Project consisted of a series of survey research studies to examine types, amounts, and characteristics of activities affecting parent involvement in early childhood programs funded by the Handicapped Children's Early Education Act. These included the Model Project Study conducted in 1978, the Parent Satisfaction Study I conducted in 1979, the Parent Involvement Policy Study and the Parent Participation Study conducted in 1979-1980, the Parent Satisfaction Study II conducted in 1980-1981, and the Comparative Study of Parent Involvement conducted in 1981-1982. These are described below.

Model Projects Study

Purpose. The purpose of this study was to identify parent participation activities that were being offered in model preschool programs for handicapped children and to compare the types of involvement with the involvement mandated by the HCEEP regulations. The study was also designed to obtain opinions of service delivery personnel on the importance of various parent involvement activities.

Sample. The survey sample consisted of directors of nine former HCEEP demonstration projects that were subsequently funded by the Office of Special Education for outreach activities. The projects were selected to reflect a variety of delivery systems, handicapping conditions, and ages. There was no randomization in selection, nor were the results of this study generalizable beyond the sample population. The programs chosen had been in operation for five years under the HCEEP regulations and therefore represented programs that would be exemplary in their implementation of the regulations concerning parent involvement.

Instrumentation. The Carolina Activities for Parent Survey (CAPS) used in this study was an investigator-designed telephone survey. Part I is composed of questions about program characteristics such as number of children served, types of handicaps, ages, and so on. Part II seeks information on the percentage of parents involved in 22 activities for parents in addition to the director's rating of the importance of those activities.

Procedures. Directors of the nine projects were telephoned to determine if they would participate in the study. The 20-minute phone survey was administered one week after the directors had received a copy of the survey. Two of the nine projects surveyed were also site visited by two researchers within one month after the phone surveys were conducted. The purpose of the site visit was to document information obtained by the CAPS.

Results. All nine projects had active parent participation with each program reporting at least 10 activities in which parents were involved. An average of 90% of the parents in these preschools were involved in some type of services from the program. Amount of parent participation did not vary with the program characteristics of child age, location, delivery system, parent income, and education. Two programs from urban areas, with low-income families and less educated parents, accounted for the lowest amounts of parent involvement. Results are reported in Hocutt and Wiegerink, in press.

Parent Satisfaction Study I

Purpose. This study was designed to determine the factors which might be related to parent satisfaction with a preschool program for the handicapped. The relationships between parent satisfaction and five factors (or sets of factors) were assessed: 1) amount of parent involvement; 2) parent's perception of severity of child's handicap, 3) agreement of parent and teacher perceptions of severity of the handicap, 4) selected social/demographic characteristics of the parent, and 5) selected characteristics of the child.

Subjects and Procedures. An investigator-designed survey, The Carolina Parent Survey, was mailed to 80 parents of handicapped preschool children enrolled in a home-based preschool program (see Hocutt, 1979, regarding validity and reliability of this instrument.) Fifty-nine, or 73% of the parents, consented to participate in the study and completed and returned the survey. Information was also collected on the children of these parents from program records, and a checklist completed by the child's teacher.

Results. Mothers who worked more than half-time outside the home were more satisfied with the preschool than mothers who did not. The association of parent satisfaction with other demographic characteristics approached significance. These variables included the sex of the child (mothers of boys were more satisfied than mothers of girls), the religion of the mother (Catholic mothers were more satisfied than non-Catholic mothers), and the education of the mother (those with more than a high school education were more satisfied than those with less than a high school education) (Posante, 1978).

Parent Involvement Policy Study

Purpose. The purpose of this study was to clarify HCEEP parent involvement policy by soliciting expert opinion. A Delphi procedure was used to identify, collate, and prioritize experts' interpretations of the practical meaning of HCEEP law and regulations regarding parent involvement.

Panel selection and characteristics. The panel of experts were nominated by members of the CIREEH advisory board. Nominees fell into one of the following categories: Congressional staff, Special Education Program staff, parents of handicapped children, validated HCEEP project staff directors, and experts in early childhood education and parent involvement. They also had to meet specified criteria concerning experience in parent involvement or with the Education of the Handicapped Act.

Procedures. The panel was queried using the Delphi method. This is a three-stage survey procedure used for developing consensus among independent and geographically separated people. The first questionnaire was open-ended and asked: "What parent involvement activities do you think constitute effective and meaningful parent involvement in early education projects for handicapped children?" The second questionnaire asked the following question: "What rank of importance do you believe would be given to the implementation of *each* activity in order to fulfill the mandate/policy of parent involvement in First Chance Network projects?" In addition, respondents were asked to specify the percentages of parents they would expect to find in each activity (activities were taken from responses to the first questionnaire). The third questionnaire was based on only those activities for which agreement was not statistically significant; it asked essentially the same questions as the second questionnaire. The statistic used was the Kendall Coefficient of Concordance, W, a descriptive measure of the extent of agreement among panelists.

Results. The expert panel identified 34 different parent involvement activities, 19 of which were considered to be Important (2.0) or Very Important (3.0) (see Table 7-1). The majority of these activities involved parents in rather passive roles (e.g., receive instruction in educational techniques to use with child). A few others (N = 8) involved parents in more active roles. Only three of the activites rated as Important or Very Important gave parents an opportunity for input into project decisions.

The degree of consensus among the experts about the clarification of the policy was high; the prototypic project could be considered the standard for parent involvement practice in First Chance Network projects as defined by the Delphi experts. Results of this study are reported in Hocutt and Wiegerink (in press), and Hocutt, McKinney and Wiegerink (1982).

Parent Participation Study

Purpose. The purpose of this study was to survey and document the parent involvement activities of third-year HCEEP projects and to examine additional factors associated with implementation of parent involvement. Third-year projects were chosen because they had been in operation long enough to have had their parent activities firmly in place.

Method. Thirty-four third-year projects were surveyed to determine the types and amounts of parent involvement. The Parent Involvement Survey, based on the model project survey, was designed to obtain information on the projects themselves (e.g., number of children enrolled, number of children on whom family data was reported, whether transportation was provided for parents) and required directors to report the percentages of parents involved in specific activities. There was space for the projects to list activities and amounts of involvement for any activities not specifically listed in the survey. When the Delphi study generated additional activities, a follow-up instrument was designed. While 28 projects (82%) responded to the orginal Parent Involvement Study, only 23 (67%) responded to the follow-up.

Table 7-1

Importance of Each Activity in Prototypic Project and Percentage of Expected Parent Involvement

Activity (Parents should:)	Rank	Mean Importance ***	Mean Percent Involvement	Range of Percent Involvement
Participate in development of child's IEP.	1	2.95	97.5	95.0 - 100.0
Receive information regarding support services or programs offered by other agencies.	2	2.90	97.0	85.0 - 100.0
Receive systemative reports of child's progress.	3	2.90	94.3	82.5 - 100.0
Receive information concerning the legal rights of child and parents.	4	2.88	85.0	68.7 - 100.0
Receive instruction in educational techniques to use with child.	5	2.84	85.0	68.7 - 95.0
Receive information concerning the behavioral and/or other effects of medicine.	6	2.72	77.0	50.0 - 100.0
Work with child at home to carry out the child's educational or therapeutic program.	7	2.70	84.1	73.1 - 91.2
Meet with child's teacher for informal exchange of information about the child.	8	2.70	82.6	62.5 - 100.0
Observe child in activities at home at the request of project staff.	9	2.68	84.5	75.0 - 95.0

Table 7-1 (Continued)

Activity (Parents should:)	Rank	Mean Importance	Mean Percent Involvement	Range of Percent Involvement
Receive a formal orientation to the project (philosophy, methodologies, services, etc.).	10	2.60	74.8	47.5 - 100.00
Assist in the screening/assessment of their own child.	11	2.53	83.4	65.6 - 100.0
Assist in setting project goals and objectives.	12**	2.45	69.4	65.0 - 78.1
Be members of project advisory board.	13**	2.45	34.3	7.7 - 51.2
Participate in project evaluation activities.	14	2.33	74.6	53.7 - 88.7
Receive instruction in normal/exceptional child development.	15	2.28	73.0	62.5 - 82.5
Participate in parent discussion groups to discuss problems associated with having a handicapped child.	16	2.23	64.8	57.5 - 76.2
Receive regularly scheduled home visits.	17	2.20	77.3	57.5 - 97.5
Receive their own (the parents' individualized) program.	18**	2.15	69.3	43.7 - 81.2
Observe their child at the preschool on a regularly scheduled basis.	19**	2.15	69.0	36.2 - 80.0
Be provided with a systematic means of communication with each other.	21	1.88	47.3	18.7 - 65.0

Table 7-1 (Continued)

Activity (Parents should:)	Rank	Mean Importance	Mean Percent Involvement	Range of Percent Involvement
Receive counseling or therapy.	21	1.88	47.3	18.7 - 65.0
Receive instruction to improve their general parenting skills.	22	1.88	44.1	28.7 - 55.0
Work with their child at the project to carry out the child's educational or therapeutic program.	23	1.80	48.3	18.7 - 71.2
Instruct or train other parents.	24	1.65	34.6	16.2 - 57.5
Assist as volunteers (with field trips, etc.).	25	1.45	27.4	15.6 - 45.0
Participate in project demonstration/information dissemination activities.	26	1.37	28.0	21.2 - 38.7
Observe other children at the preschool on a regularly scheduled basis.	27	1.35	42.8	23.7 - 60.0
Teach other children at the preschool.	28	1.05	22.3	12.5 - 28.7
Make instructional materials for their child.	29	1.00	28.8	7.5 - 62.5
Assist in decision-making process concerning project personnel.	30	0.80	23.4	2.5 - 52.5
Make instructional materials for other children in classroom.	31**	0.78	14.4	7.5 - 30.0

Table 7-1 (Continued)

Activity (Parents should:)	Rank	Mean Importance	Mean Percent Involvement	Range of Percent Involvement
Assist with fund-raising activities.	32**	1.88	44.1	28.7 - 55.0
Assist in decision making concerning project budget.	33	0.73	17.0	5.0 - 26.2
Work as paid staff members at project.	34	0.53	11.1	6.2 - 25.0

** These activities are tied according to the mean value of importance. The activity which appears first has the highest percentage of expected parent involvement.

*** The values of importance are as follows:

3 = Very Important 1 = Slightly Important

2 = Important 0 = Unimportant

Results. There was a wide range of project characteristics: the projects served between 13 and 250 children and between 33% and 100% of the children's parents; they enrolled all ages of children between birth and 8 years of age; they served the entire range of handicapping conditions; and they were home-based (N = 3), center-based (N = 7), and some combination thereof (N = 18). In addition, the projects were urban (N = 9), rural (N = 9), suburban (N = 5), or a combination of these (N = 5). The projects provided 34 different activities which can be grouped into the categories of parent training, therapeutic or education components (passive and active), and planning.

The survey of third-year projects found parent involvement greatest (59%) in the more passive activities (i.e., receiving a service, observing the child at home, meeting the teacher). Nearly as high a percentage of parents, however, were involved in parent training activities (58.8%). Only 15% of parents were involved in planning, development, operation, and evaluation activities (including information dissemination).

None of the most common activities offered by third-year projects were in the planning, development, operation, and evaluation category. The only activities offered by all projects were parent participation in the development of the child's Individualized Education Plan (IEP) and orientation to the project for parents.

There were nine activities in which an average of 80% or more of all parents were involved; of these nine activities, seven were also the ones most commonly offered by projects. All parents in all projects received systematic reports of the child's progress. Ninety percent or above of all parents received a formal orientation to the project, met with the teacher for an informal exchange of information, received instruction in educational techniques to use with the child, and assisted in the screening or assessment of the child. Over 80% participated in the development of the IEP, received information regarding other support services, observed their child at home, and received information concerning legal rights.

Data from the 28 projects provide the following statistically significant patterns: small projects (8) with fewer than 25 children appearing to have a higher percentage of average parent involvement per activity (69%) than do larger (6) projects with over 70 children (46%). Projects sponsored by private, nonprofit organizations (16) have a higher percentage of involvement (65%) than do those (12) sponsored by public schools (47%). Projects (12) with a staff member designated to work with parents at least 75% of the time have higher parent involvement (68%) than do projects (13) with a staff member spending less than 75% of the time on parent involvement (50%) and projects (3) with no parent staff (30%).

Results of this study are reported in Hocutt and Wiegerink, in press.

Parent Satisfaction Study II

Purpose. The purpose of this study was to determine the level of satisfaction experienced by parents served in HCEEP projects. In addition, the study was designed to document the amount of parent involvement in projects and to determine if the level of parent satisfaction varied with amount and type of involvement or with family and child characteristics.

Method. Each of the 23 HCEEP projects which responded to the parent involvement survey was asked to participate in the parent satisfaction study. Projects were sent 10 copies of the Carolina Parent Questionnaires (Posante-Loro & Wiegerink, 1978) and instructions for randomly selecting 10 parents who had been served by the project for at least one full year. Parents were mailed the questionnaire and given a stamped envelope by which they could mail the questionnaire directly to the investigators in Chapel Hill. Each questionnaire contained codes that identified both the project and the individual parents.

Results. Thirteen of the 23 projects participated by distributing the parent satisfaction surveys, and 77 of the 130 parent surveys were returned.

The parents' response to the satisfaction questionnaire indicated a relatively high level of satisfaction: 4.35 on a 5-point scale, with a range of 3.33 to 5.00. Six of the parents provided all 5's on the 9-item scale, indicating they were very satisfied with all aspects of the program. Because the response of projects and parents was only slightly over 50%, a response bias in favor of those projects and parents most positive about parent involvement could be present in the results. These positive findings do, however, replicate the findings of the Batelle Report (1976) and the Posante-Loro study (1978).

Respondents did provide variations in their responses. The range of responses allowed for the most satisfied (N = 15), and least satisfied (N = 17), parents to be compared (see Table 7-2) Projects represented by three or more parents in each group did not differ on such characteristics as urbanity, income of parents, and model of service delivery, but they did differ in other ways.

Most satisfied parents, in comparison with least satisfied parents: (1) were in private, non-profit organizations rather than

82

Table 7-2

Data Comparing the More and Less Satisfied Parents

(N = 32)

Data of Parents	Least (N = 17)	Most (N = 15)
Level of satisfaction of parents on a five point scale (5 being high)	3.8 mean 3.3-4.0 range	4.9 mean 4.8-5.0 range
Level of involvement of parents per month		
At preschool	9.0 hours	11.4 hours
At home	52.0 hours	42.0 hours
With other parents	1.6 hours	4.6 hours
Average time in program	21.7 months	17.8 months
Projects represented		
Number of projects with parents	9	8
Projects with more and less satisfied parents	6	6
Type of child handicap		
Physically handicapped	18%	20%
Developmentally disabled	35%	73%
Multiply handicapped	47%	7%
Child variables		
Sex male	65%	80%

Table 7-2
(Continued)

Data of Parents	Least (N = 17)	Most (N = 15)
Child variables (Continued)		
Average age	51 months	45 months
How much say do the parents feel they have?		
Educational decisions	82%	80%
Program decisions	6%	73%
Percent of child improvement reported by parents	100%	100%

public schools; (2) were more involved in the programs; (3) spent more time working with other parents; (4) had a lower proportion of multiply handicapped children and higher proportion of developmentally delayed children; (5) were more often parents of boys; and (6) felt they had acceptable levels of influence on the program or wished for additional influence. Results of this study are reported in Hocutt, McKinney, and Wiegerink (1982).

Comparative Parent Involvement Study

Purpose. The purposes of this study were to conduct comparative analysis of the following two points: (1) to determine discrepancy between levels of involvement recommended by experts and levels of involvement reported by two groups of projects: those sponsored by public schools, and those sponsored by other types of organizations; and (2) to determine whether or not there is a relationship between levels of involvement reported by staff and parents in the two groups of projects, and selected project, parent, and child characteristics.

Methods. HCEEP projects which served parents of handicapped children were placed into two groups: those sponsored by public school systems and those sponsored by other agencies. They were then matched according to year of funding and size of project (i.e., approximate number of children served). In general, the public school projects served much greater numbers of children. From these matchings, a sample of each was drawn: 21 public school programs and 19 other-sponsored programs were selected. These projects were then surveyed regarding types and amounts of parent involvement, goals of involvement, and barriers to involvement using the *Parent Involvement Survey Instrument*. In addition, a sample of five parents from each project was drawn and surveyed with the *Parent Needs and Involement Survey* to determine type and amount of involvement, goals of involvement, and barriers to involvement. The instruments used were developed as a result of earlier studies and were examined for the validity and reliability found to be adequate for survey purposes.

Results. The projects sponsored by the two categories of agencies did not differ statistically on any of the characteristics nor did they vary on cost per pupil, type of cachement area, type of child served, severity of child conditions served, parent income, or number of parents in the home. They did differ in that: (1) no black parents responded from the other-sponsored projects, although 11 of 32 parent respondents from the public school projects were black; (2) other-sponsored projects had more parents who were married and together; and (3) there was a trend for other-sponsored parents to be better educated.

Parent participation in these two groups of projects was then compared to the parent involvement prototype described in the above section on the parent involvement policy study. Public school sponsored projects were more congruent with the Delphi prototype in that they met criterion on a *greater number* of activities both for all activities and for each category of activity. Other-sponsored projects were more congruent in that they reported *higher levels of involvement* in all four categories and were therefore closer to actual expected levels.

Relationships between levels of involvement and project, parent, and child characteristics were examined. Level of funding was not predicted by: year of funding, size, costs per pupil, full-time equivalency of staff working with parent, parent education, race, severity of child's handicap, or length of service time. There were trends indicating that, for public school projects, the older projects had more parent involvement and that, for other-sponsored projects, the size of the program positively correlated with amount of parent involvement.

In both types of projects, parents reported involvement in fewer activities than those that projects' staff reported offered. Though the result was statistically significant, the overlapping curves in the distributions indicate these differences were not great and probably not educationally meaningful. An examination of goals for involvement and barriers to involvement produced the following trends:

The goal most often selected by both groups of projects as *the* major goal of the project was, "To enable parents to act as change agents for their child." Both sets of projects cited limited staff time as a major reason for not offering more parent involvement activities. Project staff from both sets of projects cited lack of transportation and employment outside the home as the primary reasons for parental non-involvement; public school staff also mentioned the need for parents to care for others in the home. Parents from both sets of projects also selected acting as a change agent as the primary reason for involvement. However, while selection of this goal was overwhelming for public school staff (17 out of 21), it was not overwhelming for public school parents (6 out of 21), who also wanted to "help plan my child's special educational program." Discrepancies found between parents and staff regarding goals were as follows: (a) no staff selected behavior management as the major goal; some parents did in both sets of projects; (b) no staff selected *project* planning and evaluation; some parents from both sets did; (c) no staff selected planning child's educational programs as the top goal; several parents did from both sets; and (d) staff were far more interested in providing parents with counseling and emotional support than were parents (2 out of 64).

The discrepancies between parents and staff regarding barriers were as follows: (a) staff thought transportation a greater barrier than did parents; (b) "other" parents named respite care the top barrier while "other" staff did not name it at all; (c) a couple of "schools" parents did want educators to make decisions, a desire not cited by school staff. Two items of congruence among staff and parents were (a) that employment was seen and named as a major barrier and (b) that no parent and no staff named lack of parent control as being a barrier.

Results of this study are reported in Hocutt (1979) and Hocutt and Wiegerink (in press).

Discussion

There was a remarkable degree of concurrence among these studies on parent involvement in HCEEP projects. Four areas of agreement are especially notable. First, parent involvement consists of a wide range of activities to provide parents with information and emotional support, to train parents, and to involve parents in decision-making.

Second, there is great variation in the extent to which parents are expected to be, and are involved, in activities. The mean percentage of parent involvement expected for specific activities in the ideal project created by the Delphi procedure did not always agree with the actual involvement found in either the model or third-year projects. Nevertheless, involvement was heaviest in the areas in which the most participation was expected; namely, parent training and educational/therapeutic activities.

Third, those activities rated most important to implement by both the Delphi panelists and the service providers were the ones which had the most involvement and in which the most involvement was expected. As a whole, these activities placed parents in roles in which they either received information and services or acted as educators of their own child.

Fourth, very low priority was given to parent involvement in the decision making function and activities by professionals. In view of the emphasis placed on parent power and active consumer involvement, particularly in recent legislation such as the Education of All Handicapped Children Act, it is surprising that these functions were given such low ratings by both Delphi panelists and program directors. In part, this finding is a result of the fact that programs traditionally have not been organized to include a large number of parents in decision making and program implementation. Nevertheless, it was clear that parent involvement in decision making was not viewed as being as important as their involvement in more traditional roles.

Two other findings might be noted. First, the study of model projects produced no statistically significant differences between the amounts of parent involvement in projects which varied by handicapped population served, service delivery models, or parental income and education. However, this study did show a trend toward less parent involvement in urban projects which served low-income families. The implementation study, on the other hand, produced a number of suggestive findings regarding the impact of project characteristics on the extent of parent involvement. More involvement was found in projects which were small (less than 25 children served), which were sponsored by agencies other than the public schools, and which had staff specifically designated to work with parents for at least 75% of their time. As opposed to the model study, data from the implementation study demonstrated that urban projects had the highest levels of parent participation. The implementation study did confirm earlier findings that the service delivery models used by projects did not differentially affect amounts of parent involvement.

A second finding is that, in spite of the low priority given to parent participation in decision making activities by the Delphi panelists and the projects, an important difference between the most and least satisfied parents was that the most satisfied saw their involvement with decision making as adequate, or wished for more involvement, whereas the less satisfied parents had no such involvement.

The policy of parent involvement, as embodied in the law and regulations of the Handicapped Children's Early Education Program, was clarified by remarkable consensus among the Delphi panelists. Further, the practice of parent involvement in these projects is reasonably congruent with the amount and types of involvement that would characterize a model project as defined by the Delphi procedure.

The final study comparing parent involvement in public school sponsored and other agency sponsored projects found high levels of parent involvement both in terms of number of activities in which parents participated and in percentages of parent participating in them. The overall profile of parent participation approximately equals what the experts in the policy study determined as standards for such participation. Recognizing that each of these studies drew different samples; there was a trend toward more parent participation in each succeeding year of the five years of study. In particular, the public school sponsored projects in the comparative study reflect a substantial increase in parent involvement from the earlier studies.

From the limited number of significant correlational findings throughout the studies, it would be safe to say that the amount and type of parent participation in individual projects is a relatively unique result of individual project goals, perceived barriers, and implementation attempts. In practice, parent participation is not so much a matter of attempting to reach a common professional standard which applies globally as it is a matter of matching project and parent choice. Parent participation reflects the fact that what you do is what you get. Parent participation does not appear to be enhanced or limited by project, child, or parent characteristics but is rather a function of individual parent and staff goals.

Recommendations

It is recommended that for knowledge in the area of parent participation to further develop, model projects with substantially different types of parent participation be compared by following samples of parents through each program on a longitudinal basis. This would be necessary in order to measure the direct impact of parent participation on parents and indirectly on children. Survey data are useful as an initial step in describing parent involvement and related factors, but they are no more than suggestive of the functional effects of parent involvement. Studies to examine such effects would need substantial resources committed over an extended period to tease out meaningful, functional relationships and impacts.

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(CIREEH products, cited in this section, are referenced in the Products List in Chapter 13.)

CHAPTER 8

Parental Perspectives of Preschool Mainstreaming

Ann Turnbull, Jan Blacher, Judith Leonard, & Pam Winton

Background and Purpose

Although mainstreaming and parental involvement are paramount in the delivery of educational services to young handicapped children, limited attention has been directed to parental values, needs, and outcomes associated with mainstreaming. The purpose of this component of CIREEH has been to systematically identify parents' perspectives on preschool mainstreaming as a precursor to an analysis of policy implications and development of training materials for parents of preschool handicapped children. The accomplishments of the project fall into three categories: empirical and conceptual reviews, research studies, and development of a parent handbook.

Empirical and Conceptual Reviews

The first year of the project was primarily devoted to a comprehensive review of the literature and the development of a conceptual framework to guide the investigation of parental perspectives of mainstreaming. Five papers (Blacher, Leonard & Turnbull, in press; Blacher & Turnbull, 1979; Turnbull & Blacher, 1980; Turnbull & Blacher, in press; Turnbull & Leonard, 1981) and three conference presentations resulted from this work.

Research Studies

Comprehensive Survey of Mainstreaming in Preschool Programs

A survey of mainstreamed First Chance programs and Region IV Head Start programs was conducted. The purposes of this survey were as follows: to clarify theoretical and operational definitions and goals of preschool mainstreaming, to examine teacher attitudes toward mainstreaming, teacher preparation for mainstreaming, parent involvement, nature of curriculum and architectural design, and administrative arrangements in mainstreamed preschools.

Subjects. Project directors and teachers in 22 mainstreamed First Chance classrooms and 110 Region IV Head Start programs participated in the survey.

Instruments. Two assessment instruments were developed for this study (Turnbull, Blacher & Leonard, 1978(a); Turnbull, Blacher & Leonard, 1978(b)). One questionnaire focused on administrative arrangements and was filled out by project directors. The second questionnaire focused on classroom implementation of mainstreaming and was completed by teachers.

Results. Findings indicated high levels of similarity between the two models on mainstreaming implementation. Although high levels of agreement were reported on the general goals for preschool mainstreaming (e.g., handicapped children learn socialization and language skills from nonhandicapped children, nonhandicapped children learn to develop sensitivity toward individual differences), teachers in both models reported uncertainty in regard to whether parents of handicapped and nonhandicapped children believe that mainstreaming settings are most appropriate for their children. These findings have been reported in three papers (Blacher & Turnbull, in press (a); Blacher & Turnbull, in press (b), Turnbull & Blacher, 1979) and in one conference presentation.

Two-Phase Interview Study of Mothers of Preschool Handicapped Children

The purpose of this descriptive study was to assess parents' perspectives on preschool services, mainstreamed and specialized. A two-phase interview strategy, drawn from the ethnographic tradition, was employed in gathering data.

Subjects. Thirty-one mothers of mildly or moderately handicapped children, 14 of whom had handicapped children enrolled in specialized preschools and 17 of whom had handicapped children enrolled in mainstreamed preschools, participated in this study.

Instruments. During Phase I of the study a focused interview was conducted with mothers regarding the factors which influenced their choices of preschools, their evaluation (benefits and drawbacks) of their child's current preschool and their attitudes towards mainstreaming. This qualitative information was coded and quantified. A questionnaire, based upon the information which emerged during the focused interview, and information from another CIREEH study on parent involvement (Wiegerink & Posante-Loro, 1979), was developed and administered to parents during Phase 2 of this study (Winton & Turnbull, 1981).

Results. 1. Parents' understanding of the term "mainstreaming." Even though one-half of the parents in this sample had children in mainstreamed settings, parents varied tremendously in regard to their understanding of the term mainstreaming. This suggests that professionals working with parents in decision-making situations should not assume that all parents are familiar with this term. It also suggests that more efforts should be made to provide parents with information on mainstreaming to assist them in their new role as an educational decision maker.

2. Parental stress associated with the choice of mainstreaming. Two sources of parental stress were identified as being associated with the choice of mainstreaming. One was the presence of what parents described as an adjustment period, related to their children's handicapping conditions, which occurred when their children were first enrolled at their current preschools. Forty-one percent of the parents in the mainstreamed group, as compared to none of the parents in the specialized group, described adjustment problems, such as teachers and peers being afraid of or rejecting their handicapped children. What is most interesting about these adjustment problems is that no parent described them as drawbacks to their children's programs. Parents described them as problems which were resolved over time. In fact, in some cases the adjustment to preschool mainstreaming was described as being beneficial in that parents felt that it helped prepare their children for the "real world." What these parents seemed to be saying was that experiencing the "stress" of adjusting to a mainstreamed setting at an early age was better than waiting until their children were older and then "throwing them out" to what some parents described as the "cruel world."

The second area of parental stress related to the difficult task of finding a regular preschool willing to accept a handicapped child. From the perspective of parents, professionals seldom had information about which regular preschools were receptive to serving handicapped children; parents basically had to locate such preschools themselves. To keep this search for an appropriate mainstreamed preschool from being so stressful, it is suggested that parents whose children are making the transition to preschool have access to information about preschools in their community receptive to handicapped children. Federal funding could be provided to a community agency whose responsibility would be to compile and disseminate this information.

3. Parents' attitudes towards mainstreaming. Parents considered the major benefits to mainstreaming to be social ones, such as opportunities for interaction with normal peers and exposure to the "real world". The major drawbacks were in instructional areas, such as lack of individual attention and presence of unqualified teachers. This suggests the need for providing more inservice and preservice training for early childhood teachers on teaching handicapped children. In addition, efforts should be made

to provide more instructional assistance (aides, consultants, special services) to regular classrooms serving handicapped children, as well as training for regular teachers in how to use this assistance. These findings suggest that research on preschool mainstreaming, which in the past has focused almost exclusively upon social factors (Turnbull & Blacher-Dixon, in press), be directed toward instructional aspects as well.

4. Parents' perspectives on parent involvement activities. The major factor influencing parents' choices of preschools was the desire to find what was best for their children. Parents were not primarily seeking special programs and training for themselves. The major preschool benefit for parents was the opportunity to have a break from the full-time responsibilities of educating their children. Parents preferred to be involved in their children's preschools, but their preference was for informal, frequent meetings with teachers in order to share information about their children, rather than for more formalized and structured activites, such as parent training, parent groups and advisory board membership. This information supports a model of parent involvement in which services are matched with the individual needs of families, a distinction is made between involvement with child and involvement with program, and in which the definition of parent services is expanded so that informal types of involvement and opportunities for non-involvement at certain times are recognized and valued by professionals.

These findings have been reported in nine journal articles (McMillan & Turnbull, in press; Turnbull, in press (a); Turnbull, in press (b); Turnbull & Turnbull, in press; Turnbull, Blacher & Winton, in press; Turnbull & Winton, in press; Winton, in press; Winton & Turnbull, 1981) and 11 conference presentations.

Sociometric Study of Parent Interactions in Mainstreamed Preschools

The major question addressed in this telephone interview study was as follows: "Are parents of handicapped and non-handicpped children 'mainstreamed' in parental involvement activities associated with preschool programs?"

Subjects. Mothers of handicapped (n = 7) and non-handicapped (n = 28) preschoolers whose children were enrolled in one of five mainstreamed classrooms participated in this study.

Instruments. A sociometric instrument was developed to assess interaction between these two groups of parents in the mainstreamed settings.

Results. The major finding of this study was that mothers of handicapped children interact both with mothers of handicapped and non-handicapped children, but mothers of non-handicapped children choose almost exclusively mothers of other non-handicapped children with whom to interact. An additional finding was that it is extremely difficult to obtain consent from program directors and parents to conduct research on parent-parent interaction.

These findings are reported in one journal article (Blacher & Turnbull, in press).

Comprehensive Survey of Parents of Handicapped and Non-handicapped Preschoolers

The major purpose of this telephone survey (Winton & Turnbull, was to identify the informational needs and perspectives on mainstreaming of parents of handicapped and non-handicapped children in mainstreamed, public school kindergarten classrooms.

Subjects. Mothers (n = 50) of mildly/moderately handicapped children with a variety of handicapping conditions who were enrolled in mainstreamed kindergarten classrooms and mothers (n = 50) of non-handicapped children, matched according to classroom, participated in this study. The mothers represented a variety of social, economic and ethnic backgrounds.

Instruments. Telephone interviews were conducted with parents using a questionnaire which had been mailed to the participants prior to the interview. The questionnaire was a modification of one developed and used in the previous study of parents' perspectives of preschool programs (Winton & Turnbull, 1981).

Results. 1. Informational needs. Of the parents interviewed, 85% wanted more information about mainstreaming. The largest number of parents (73%) preferred printed materials as the source of additional information, as compared to TV (selected by 17%) or PTA meetings (selected by 8%).

2. Attitudes towards mainstreaming. Parents in both groups perceived the greatest drawbacks to mainstreaming as being instructional in nature and as negatively affecting handicapped children. They felt that in mainstreaming teachers are unqualified to deal with the needs of handicapped children and that the handicapped children do not receive the special help and attention they need when in mainstreamed classrooms. Parents in the two groups differed in terms of their perception of the greatest benefits of mainstreaming. Parents of non-handicapped children felt that mainstreaming helps non-handicapped children learn about differences in

the way people grow and develop. Parents of handicapped children felt that mainstreaming prepares handicapped children for the real world. These findings suggest that parents of non-handicapped children view mainstreaming as a positive rather than negative experience for their children. This information supports the results of the two phased Interview Study of Parents of Handicapped Preschoolers (Winton & Turnbull) that the drawbacks to preschool mainstreaming are instructional in nature and that the benefits are social.

Two journal articles reporting these findings are in preparation.

Development of Parent Handbook

Two messages were clear as a result of our study of parents' perspectives on preschool mainstreaming. One was that finding appropriate preschools for young handicapped children can be a difficult, frustrating and time-consuming task for parents. In most communities there is no one person or place where parents can find out about what programs are available and which children are eligible for which programs. The second message was that each fa-mily approaches this task in a unique and individual way. The idea of a source book which would serve as a decision-making guide for parents developed out of this research. The book draws together material from a variety of sources including information on laws and policies affecting handicapped children, research on preschool programs, guidelines and suggestions for educational decision-making and anecdotal accounts from parents of young handicapped children who have been through the decision making process themselves. The purpose of this book is to assist parents in making the best match between their needs and the preschools in their community.

Nine out of the proposed 15 chapters have been completed in draft form. A phased development and field testing of the handbook (see Table 8-1) is being conducted. Phases I and II have been completed. Contract negotiations with University Park Press have been completed; they will publish and market the book.

Discussion and Recommendations

When this project began, the area of preschool mainstreaming was relatively unexplored. There were no major literature reviews to guide research efforts; and in fact, no agreed upon definition as to what mainstreaming was. While there were individual research studies on preschool mainstreaming which primarily focused on measures of child outcome, there was virtually no research on parents' perspectives on preschool mainstreaming. One of the major purposes

Table 8-1

Phased Field Testing Plan for Parent Handbook

I. Exploratory Studies (conducted prior to development)	II. Process Studies (conducted early in development)	III. Product Studies (conducted after first stages of development)
A. Interviews with parents and subsequent needs analyses	A. Need for the handbook/guide established	A. Review by parents and professionals of a draft of the book using standardized questionnaire and telephone interview to assess its style, content, utility, and social fairness
B. Literature reviews on preschool mainstreaming and parent involvement	B. Format established	
C. Empirical studies of parents' preschool programming for handicapped children	C. Detailed outline of contents of book reviewed by a group of parents, teachers, trainers, and researchers	
	D. Revision of outline	

of this project was to gather information on how the choice of mainstreaming at the preschool level affects the family system and how this choice is made within the context of the neighborhood and the community.

What have we learned from our research? From the perspectives of parents, the choice of mainstreaming at the preschool level is based upon a delicate balancing of priorities, needs, values and experiences. In a sense, parents who choose mainstreaming have accepted the "normalization principle;" that is, they believe that exposure to the "real world" and interaction with normal peers at an early age will enhance their child's ability to function in normal settings as the child gets older. Even the stressful adjustment periods experienced by some handicapped children in mainstreamed preschools were viewed by some parents as being beneficial in hardening their child for the real but "cruel world." The question for parents seems to be whether their children can get this exposure in the neighborhood or elsewhere, or whether the preschool is the best setting for this opportunity, given the instructional disadvantages of mainstreamed settings perceived by parents.

The question which has not been answered by research and which needs to be addressed by further studies is "are parents correct in their assumptions?" Does early exposure to mainstreaming enhance a handicapped child's ability to function in the 'real world?' Does undergoing an adjustment period at the preschool level affect the rate, type or quality of adjustment periods in later mainstreamed settings?

In addition, research studies are needed which examine the conditions within mainstreamed settings which optimize the mainstreaming process. Why do some children undergo an adjustment period in mainstreamed preschool and others do not? Is this related to certain child characteristics?, teacher variables?, or characteristics of peers? Why do some parents go through an adjustment period and others do not? How is the rate and type of parent-parent interaction in mainstreamed settings affected by family, child and teacher characteristics?

Our research clearly indicated that parents of young handicapped children need and want more information on mainstreaming. Not only do they need information about the definition, rationale, and possible outcomes associated with mainstreaming, but they also need specific assistance in how to locate appropriate mainstreamed preschools in their communities. Because laws mandating preschool education for handicapped children vary from state to state and preschool for non-handicapped children is not mandated, parents who want to choose mainstreaming for their child usually face the difficult task of trying to locate private preschools willing to accept handicapped children.

The purpose of the parent handbook being developed as part of this project is to provide parents with information and strategies to assist them in their decision-making role at the preschool level; however, larger scale efforts are needed to stimulate the dissemination of information to parents. For instance, a certain percentage of research funds could be earmarked for dissemination as a way of promoting this activity. Federal funds could also be provided to a community agency whose responsibility would be to compile information on area preschools and distribute it to various parent organizations, early intervention programs, hospital clinics and other professionals having contact with families of handicapped preschoolers.

Information from this study which indicates that parents value competent and sensitive professionals being involved with their children's education so that they can have a break from these responsibilities for a part of the day and that they prefer involve- that is informal but permits frequent contacts with their children's teachers, has significance for those directing policy, and planning programs. Professionals often operate on the premise that they are acting in the best interest of the child in encouraging parents to be actively involved in the child's program. In making this assumption, professionals have overlooked the very legitimate need which some parents have not to be formally involved at times. In addition, professionals often fail to make the distinction between parental involvement with child, and parental involvement with program. The fact that parents indicated their favorite type of activity to be freequent but informal contacts with teachers, and reported this opportunity as being one of the major benefits of their children's preschools suggests a strong commitment to their children. Yet this activity is not one which has been emphasized in the literature on parent involvement. Professionals emphasize the importance of planning for individual differences and developmental change in programs for children. How may programs for parents reflect the same concern? Too often professionals assume that "good parents" will become involved with whatever parent activities are offered, regardless of the parents' needs or desires for such services.

It is suggested as a result of our research that parent involvement models are needed which take into account the diverse needs and perspectives of parents. Such a model might provide, at the minimum, the following graduated (less-to-more) involvement options:

a. Allow some parents not to be involved with a school program if they so choose. If patients have a right to refuse medical treatment, parents of handicapped children should have the right to decline to be education decision makers. Perhaps taking on the responsibility of educational decision making will be the greatest service the program can provide in helping some parents establish equilibrium between the stresses posed by adapting to the handicapping condition and their optimum coping skills.

b. Provide still other parents an opportunity to be informed of goals and objectives, according to the decisions made by professionals.

c. Provide full and equal decision-making opportunities for parents who choose to participate at this level.

Such a model should recognize the evolving needs of parents, and allow for flexibility in meeting these needs. Various strategies should be available to help the family address their priority concerns in learning to integrate their handicapped child successfully into the family. In essence, educational policy first should recognize, and next create, a range of options and choices for parents. It is an overly rigid policy--one that parents of handicapped children do not support uniformly--that does not respect their individuality and diverse capabilities.

(CIREEH products, cited in this section, are referenced in the Products List in Chapter 13.)

CHAPTER 9

Child Assessment Project

Rune J. Simeonsson

Background and Purpose

When handicapped infants and young children lack meaningful communication skills, function at very basic levels, and are characterized by atypical, bizarre and/or pathological behaviors, valid assessment seems difficult if not impossible. In addition to limitations attributable to the child, assessment problems of special relevance to handicapped youngsters also include: a) definitional issues; b) limitations of instruments; c) limitations of examiners; and d) limitations of analysis (Simeonsson, Huntington, & Parse, 1980). Attempts to deal with the problems of assessing handicapped infants in the past have often relied on the adaptation or modification of standard intellectual, or developmental scales. In the search for improved assessment procedures, it may be productive to consider additional strategies and domains, ones which may reflect the behavior and development of the handicapped youngster. Considerations of potential relevance to this end are a) a multivariate focus, b) capitalizing on clinical judgement, and c) documentation of behavior patterns and characteristics, particularly in the social/affective domain (Simeonsson, Huntington, & Parse, 1980).

In short, to improve assessment in early development there is a need not only to increase the number of measures but also to focus on variables such as behavior and temperament sensitive to development of handicapped infants. There is also a need to effectively utilize assessment information from parents and others with direct and continuous experience with such infants. Finally, it is important to recognize the value of documenting the "natural history" of handicapping conditions (Rogers, 1971) through repeated assessments at intervals of development. The use of multiple variables will expand the base of assessment and should reveal relationships among domains of development thereby indicating combinations of variables most effective in accounting for outcome.

Methods

Subjects. The subjects in this ongoing study were in intervention programs across the country serving handicapped children from 0-6 years of age. The overall group includes more than 360 children. However, availability of data varied for specific measures. Table 9-1 presents information on chronological and developmental age by handicapping conditions. The total number of handicaps reported for 360 children was 623, with a mean of 1.88 per child. Two hundred and fifteen (58%) of the children had more than one handicap. Severity level of the handicaps ranged from mild to profound, with 47% of the handicaps reported as severe or profound and 53% as mild or moderate.

Instruments: 1. The Carolina Record of Individual Behavior (CRIB). The CRIB is an experimental instrument developed in this project. The first part of the CRIB, designed to document the child's level of arousal, enumerates nine state levels derived from the literature (Ashton, 1973; Korner, 1972; Brazelton, 1973) ranging from deep sleep to uncontrolled agitation.

On the basis of systematic observation, state level of the child is scored in three ways: a) initially, at the beginning of the observation; b) the predominant activity level throughout the observation; and, c) all states observed throughout the observation.

The second part of the CRIB consists of three sections (A, B, & C) differentiated on the bases of behavioral domains. The CRIB can be scored in the context of an evaluation session and/or a period of systematic observation in which the child has opportunity to display a range of behaviors.

Section A measures eight different behaviors, each rated on a nine-point scale. The nine-item range was designed to be developmental in nature with 1 reflecting the most basic level and 9 the most advanced. Each of the nine items is behaviorally described in order to facilitate accurate scoring.

Section B also measures eight behaviors on a 9-point scale. The difference, however, is that the items are developed so that items 1 and 9 reflect polar opposites and 5 is the optimal value. Again, each of the nine items is behaviorally indexed.

Section C is comprised of elements from four domains: sound production, rhythmic habit patterns, affect, and exploratory behavior. The degree to which the child exhibits behaviors in each of these areas during the assessment/observation interval is rated. The characteristics are rated from 0 (not at all) to 4 (much of the time).

When scoring the CRIB is complete, scores for Sections A and B can be presented in a profile form to provide a graphic portrayal of the child's behavioral characteristics.

Table 9-1

Chronological and Developmental Ages

	Chronological Age				Developmental Age			
	N	M	Range	SD	N	M	Range	SD
Tot. Sample	360	35.6	3-89	16.0	155	14.94	1-60	12.02
Ment. Retard.	49	35.4	6-70	16.1	20	12.11	3-29	6.8
Aud. Impair.	29	38.3	13-61	10.5				
Ortho. Imp.	14	30.6	10-65	18.1	7	15.4	8-27	7.1
Down Synd.	58	29.4	3-75	17.7	28	15.0	3-42	10.2
Multihandicapped	212	37.8	10-89	15.2	95	15.4	1-60	13.4

2. Toddler Temperament Scale. The primary temperament measure used was the Toddler Temperament Scale developed by Fullard, McDevitt and Carey (1978). The scale consists of 97 statements to which the respondent replies on a 1-6 scale of almost never to almost always. The items yield scores in nine temperament categories that are used to derive the clinical diagnoses of easy, difficult, slow to warm up, and intermediate high and low.

Results

The Child Assessment Project has been an ongoing research effort collecting and analyzing developmental and behavioral measures of handicapped infants and children. The first objective was to evaluate the utility of current instruments/approaches to assess the progress of handicapped children. Research addressing this objective has focused on documenting the applicability of alternate behavioral and developmental measures to enhance assessment options in early identification/intervention efforts. The two measures of primary interest in this regard were the Carolina Record of Individual Behavior (CRIB), developed in this project, and the Toddler Temperament Scales (TTS) (Fullard et al., 1978). Note that values for the A_3 subscale of the CRIB are not presented, since that scale was significantly altered after data collection was initiated.

(a) Research on the applicability of the CRIB to handicapped infants and children. Drawing on data from more than 360 handicapped children, CRIB A & B subscale scores were examined as a function of primary handicapping conditions. From a conceptual standpoint, the validity of the CRIB was also examined to determine the extent to which the designation of scales as developmental (Section A) and behavioral (Section B) would be supported by correlational and factor-analysis evidence.

Descriptive statistics of subgroups by handicapping conditions are summarized in Table 9-2. Values for the A subscales from the subgroups revealed lower mean scores for children who were mentally retarded or who had more than one handicapping condition, whereas somewhat higher mean scores were found for children with auditory or orthopedic impairments or Down syndrome. Greater variability of scores was evident in the mentally retarded and multihandicapped groups than in the other subgroups.

A review of Table 9-2 reveals that children with mental retardation and two or more handicapping conditions also had more discrepant CRIB B subscale scores than the other three identified subgroups.

Table 9-2

Summary Statistics for CRIB A and B Subscales

	Total Sample		Mentally Retarded		Auditory Impairment		Ortho. Impairment		Down Syndrome		Multihandicapped	
	CRIB A Subscales											
	N = 312-361		N = 34-48		N = 28-29		N = 13-14		N = 45-61		N = 193-212	
A	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
1	7.2	(2.1)	6.2	(2.3)	8.3	(1.1)	7.9	(1.4)	7.8	(1.4)	7.1	(2.2)
2	5.8	(2.4)	5.3	(2.0)	7.1	(1.2)	6.5	(2.2)	6.6	(1.9)	5.5	(2.5)
4	4.8	(2.4)	4.1	(2.4)	5.9	(2.5)	5.5	(1.7)	5.1	(2.1)	4.8	(2.4)
5	5.5	(2.5)	5.1	(2.2)	7.2	(1.8)	6.9	(2.1)	5.3	(1.9)	5.5	(2.6)
6	6.2	(2.5)	5.5	(2.4)	7.5	(1.5)	8.1	(1.8)	6.4	(2.2)	6.1	(2.6)
7	6.4	(2.3)	5.6	(2.1)	8.1	(1.0)	7.7	(1.3)	6.8	(1.6)	6.3	(2.5)
8	5.0	(2.1)	4.4	(2.0)	6.6	(1.7)	5.3	(1.8)	5.4	(1.7)	4.9	(2.3)
	CRIB B Subscales											
	N = 350-364		N = 45-48		N = 28-29		N = 12-14		N = 57-61		N = 209-215	
B	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
1	4.0	(1.1)	3.8	(1.0)	4.2	(1.1)	4.5	(0.8)	4.4	(0.8)	3.9	(1.1)
2	4.0	(1.0)	4.0	(0.9)	4.5	(0.8)	4.6	(0.5)	4.4	(0.7)	3.9	(1.1)
4	3.1	(1.2)	2.4	(1.3)	3.9	(1.0)	4.3	(0.8)	3.7	(0.9)	3.4	(1.2)
5	3.7	(1.1)	3.5	(1.0)	4.3	(0.8)	4.0	(0.9)	3.5	(0.8)	3.0	(1.3)
6	4.3	(1.0)	4.1	(1.0)	4.5	(0.9)	3.9	(1.1)	4.0	(0.9)	3.6	(1.1)
7	3.7	(1.4)	3.6	(1.3)	4.8	(0.4)	4.4	(0.9)	4.6	(0.6)	4.2	(1.0)
8	4.0	(1.1)	3.9	(1.1)	4.7	(0.5)	3.8	(1.6)	4.3	(1.0)	3.5	(1.5)

Section C of the CRIB includes 36 items on which affective, exploratory, repetitive, and related behaviors are scored. For this analysis, focus was restricted to 14 of the items dealing with repetitive rhythmic habit patterns. Table 9-3 presents the percentage of children for whom rhythmic habit patterns (RHP) were reported by groups.

Using 20% as an arbitrary criterion of frequency, inspection of the table reveals that for the total group, the most frequent RHPs observed were hand/finger sucking, foot kicking, arching body, throwing body back and body rocking. For specific subgroups, the patterns and magnitude of frequent RHPs varied substantially. For children with orthopedic impairments, some RHPs were either absent or reported at a very low frequency, with the exception of arching body and throwing body back. Down syndrome children differed from every other subgroup in that the frequency of tongue thrusting was 3 to 6 times as high. It is also interesting to note that Down syndrome children were the only group for whom the frequency of arching body did not exceed 20%. Whereas hand/finger sucking and foot kicking were frequent RHPs for each subgroup except children with orthopedic impairments, body rocking was only above 20% for children with mental retardation and multiple handicaps and head rolling was only above 20% for mentally retarded children.

Correlation matrix. Two approaches were employed to document the extent to which data would support the designation of the A subscales as developmental and the B subscales as behavioral (nondevelopmental) in nature. One approach was to examine the correlation matrix of CRIB A and B subscales with chronological age and developmental age estimates for the total sample. As indicated previously, developmental age estimates were not available for all subjects included in the study; hence, correlations involving this index are based on a restricted sample size (Table 9-4). A comparison of significant correlations between CRIB A subscales and CRIB B subscales with chronological and developmental age indices respectively is presented in Table 9-4.

An inspection of the table reveals that developmental indices of chronological and developmental age were correlated more frequently and with higher values for CRIB A subscales than for CRIB B subscales. While chronological age in general showed some significant associations with CRIB subscales, developmental age estimates were correlated with all A subscales and 6 out of the 8 B subscales. The strongest associations were found between developmental age estimates and object orientation (r = .53) and expressive and receptive communication (r = .72).

Factor analysis. A second approach to examining the validity of

Table 9-3

Percentage of Children with Rhythmic Habit Patterns

HABIT PATTERNS	TOTAL N = 367	MR	AUD	ORTH.	DOWN	MH
Hand/finger sucking	40.9	53.1	31.0	7.1	42.6	41.1
Foot kicking	34.9	30.6	24.1		31.1	40.7
Lip biting	7.6	8.2	14.0		6.6	7.5
Body rocking	22.1	30.6	14.0	7.1	14.8	24.3
Pica	9.0	8.2	10.3		3.3	11.2
Head rolling	12.3	20.4	3.4		6.6	14.0
Head banging	7.6	8.2	6.9		1.6	9.8
Tooth grinding	16.3	16.3	13.8	7.1	8.2	19.6
Hair pulling	11.2	12.2	13.8	7.1	9.8	11.2
Breath holding	1.9	2.0	10.3			1.4
Ruminating	4.6		3.4			7.5
Tongue thrusting	19.6	14.3	10.3	7.1	44.3	15.9
Throwing body back	26.4	16.3	31.0	28.6	13.1	31.8
Arching body	27.0	20.4	24.1	28.6	13.1	32.7

Table 9-4

A Comparison of CRIB A Subscales and CRIB B Subscales on Significant Correlations with Chronological and Developmental Age Indicies

Subscales	Chronological Age (N = 348-358)		Developmental Age Estimates (N = 149-155)	
	r	p	r	p
A1			.37	.0001
A2	.10	.05	.41	.0001
A3	.11	.05	.28	.001
A4			.31	.0001
A5	.34	.0001	.72	.0001
A6	.35	.0001	.72	.0001
A7	.12	.05	.53	.0001
A8			.22	.01
B1	.16	.01	.32	.0001
B2			.29	.001
B3			.39	.0001
B4	.14	.01	.30	.001
B5			.29	.001
B6				
B7			.22	.01
B8	.14	.01		

the CRIB in terms of the designation of subscales as developmental (A) and behavioral (B) was to carry out a factor analysis of the data.

The correlation matrix of the A and B variables available for 237 subjects was factor analyzed by iterated principal axis methods. The factors and loadings of items for a four-factor solution derived from a varimax rotation are presented in Table 9-5 showing differentiation of factors on the basis of A and B subscales. The first factor consisted of 3 A variables with primary loadings and one with a secondary loading. The highest primary loading (.79) was for participation and the lowest (.52) was for object orientation.

The second factor was composed of three A variables, the two communication scales and object orientation. The third factor consisted of three B variables, goal directedness frustration and attention. The two variables of reactivity and responsiveness to examiner loaded on the fourth factor.

(b) The applicability of temperament measures in assessment of handicapped children is demonstrated by the summary of the temperament scores for subgroups of handicapping conditions in Table 9-6. Comparison of handicapped children with a non-handicapped reference group of 24-36 months reveals only two values for the handicapped being greater than one standard deviation from the mean.

Finally, distribution of handicapped children according to diagnostic clusters proposed by Fullard et al. (1978) is summarized in Table 9-7. The results indicate that a smaller percentage of handicapped children are rated as difficult and a greater percentage are rated as easy when compared with non-handicapped peers. The second overall objective focused on the analysis of the contribution of clinical judgment in assessment of child status and outcome. One approach to this objective examines the correspondence of child assessments made by individuals having different experiences/perspectives with a handicapped child.

In a collaborative study (Blacher-Dixon & Simeonsson, 1981) a comparison was made of the assessments of 52 mothers of preschool handicapped children and teachers of these children. Mothers and teachers independently completed the CRIB following a period of observation. This process was repeated approximately 6 months later with 25 of the children. Significant correlations were found between parent and teacher for A variables with values ranging from .27 for consolability to .83 for expressive communication. The associations between maternal and teacher assessments were maintained at follow-up with stronger associations for 4 of the 5 significant correlations (range .55 - .91).

Table 9-5

Factor Loadings Greater Than .40 for A and B Subscales of the CRIB (N = 327)

CRIB ITEM		FACTORS			
		FACTOR 1	FACTOR 2	FACTOR 3	FACTOR 4
Social orientation	A1	.592			
Participation	A2	.728			
Endurance	A4	.703			
Child's communication (expressive)	A5			.822	
Child's Communication (receptive)	A6			.785*	
Object orientation	A7	.520*		.585*	
Consolability	A8				
Activity	B1				
Reactivity	B2				.597
Goal directedness	B3		.643		
Frustration	B4		.659		
Attention	B5		.459		
Responsiveness to caretaker	B6				
General tone or tension of body	B7				
Responsiveness to examiner	B8				

(*Secondary loadings)

Table 9-6

Mean Temperament Characteristics of Subgroups of Handicapped Children and as a Total Group

(MR=Mentally Retarded AI=Auditory Imparied OI=Orthopedically Impaired DS=Down Syndrome MH=Multi-handicapped)

SCALE		ACT		RHYT		APPR		ADAPT		INT		NEG MOOD		PERS		DIST		LOW THRSH	
GROUP	N	X	SD	X	SD	X	SD	X	SD	X	SD	X	SD	X	SD	X	SD	X	SD
MR	42	3.8	0.86	2.8	0.81	2.8	0.98	3.2	0.88	3.6	0.75	3.2	0.79	4.3*	0.80	3.9	1.01	3.8	0.88
AI	26	4.1	0.64	2.8	0.77	2.8	0.96	3.3	0.70	3.9	0.62	2.9	0.61	3.3	0.74	3.7	1.01	4.4	0.84
OI	14	3.5	0.56	2.6	0.79	3.0	0.81	2.8	0.80	3.8	0.74	2.7	0.63	3.5	0.76	3.9	0.86	3.8	1.13
DS	51	3.6	0.88	2.4	0.77	2.7	0.75	2.8	0.79	3.3	0.65	2.9	0.69	3.5	0.87	3.6	1.17	3.8	0.95
MH	173	3.4	0.98	2.7	0.76	3.1	0.97	3.1	0.85	3.6	0.82	3.1	0.74	3.8	0.99*	3.7	1.04	3.9	1.00
Total	298	3.6	0.92	2.7	0.77	2.9	0.94	3.1	0.84	3.6	0.77	3.0	0.73	3.8*	0.94	3.8	1.04	3.9	0.97
Reference Group 24-36 mo.		3.9	0.86	2.8	0.77	2.9	1.04	3.0	0.79	4.1	0.82	2.9	0.65	2.8	0.75	4.2	0.73	4.4	0.87

*Values greater than 1 SD beyond mean of non-handicapped reference group (24-36 mo) (Fullard et al., 1978)

Table 9-7

Distribution of Diagnostic Clusters

		Difficult	Easy	Slow to Warm Up	Intermediate, High or Low
Non-Handicapped Reference Group	N=187	22 (12%)	67 (35%)	21 (11%)	75 (40%)
Handicapped	N=310	22 (7%)	151 (49%)	36 (12%)	101 (32%)
Mentally retarded	N=45	6 (13%)	18 (40%)	6 (13%)	15 (33%)
Auditory handicap	N=27	2 (7%)	12 (44%)	3 (11%)	10 (38%)
Orthopedic handicap	N=14	1 (7%)	7 (50%)	3 (21%)	3 (21%)
Down syndrome	N=51	2 (4%)	28 (55%)	5 (10%)	16 (31%)
Multi-handicap	N=173	11 (6%)	86 (50%)	19 (11%)	57 (33%)

In a recent dissertation study, Baxter (1982) compared the child appraisals of mothers, teachers and a psychologist for 29 preschool handicapped children. Each child was appraised on the CRIB by the three raters independently, following a joint 3 minute observation. A summary of the correlations of appraisals between the three raters indicated that a significant correspondence of ratings was obtained across raters, although the frequency and strength of significant correlations varied for specific comparisons.

The findings reported by Blacher-Dixon & Simeonsson (1981) and by Baxter (1982) provide support for the premise of correspondence in the clinical insights and judgments of individuals with different experiences/perspectives on the handicapped child. The third overall objective sought to identify the contribution of these alternate behavioral and developmental data as predictors of outcome status. The outcome status of 290 of the children was obtained and is summarized in Table 9-8. Two kinds of analyses were carried out to evaluate the predictive utility of the CRIB and the temperament measures. For children still in the original programs a qualitative index of progress was defined by staff as more than expected, expected or less than expected. Discriminant factor analyses were carried out for several combinations of CRIB and temperament variables using these as qualitative outcome criteria. Table 9-9 provides a summary of the accuracy of outcome classification as a function of specific discriminant models. Examination of the models reveals that the use of the CRIB A and B variables or the combination of CRIB B variables with temperament variables as predictors result in the highest accuracy of classification of the calibration data. The accuracy of classification varies as a function of the prediction variable combination. The best classification is obtained with the combination of temperament data with the CRIB B subscales. These analyses provide support for the importance of multivariate documentation of child status.

In a second analysis of children no longer in the original programs, outcome status was coded in an ordinal fashion along the lines proposed by Deno (1973), from most restrictive to least restrictive placements collapsing across preschool and school age populations (private & public settings). Discriminant factor analyses of these data were similarly carried out using a combination of CRIB and temperament variables as predictors of outcome status. Table 9-10 provides a summary of the accuracy of outcome classification as a function of specific discriminant models. Examination of the models reveals that CRIB A and B variables in combination contribute to a more accurate classification of calibration data than the combination of either subscale with temperament data.

Table 9-8

Child Assessment Project: Follow-Up Survey

STILL IN PROGRAM: 93 children

Less than expected progress:	Expected progress:	More than expected progress:
24	42	27

NO LONGER IN PROGRAM: 197 children

Other Preschools:	
Preschool/Day care for handicapped children:	30
Preschool/Day care for non-handicapped children:	9
Kindergarten for non-handicapped:	5
Public School:	
Regular class without resource services:	8
Regular class with resource services:	9
Part-time special class:	10
Full-time special class:	75
Special school:	16
Non-Public School: (Private/Parochial)	
Regular class without resource services:	2
Regular class with resource services:	0
Part-time special class:	1
Full-time special class:	1
Special school:	0
Home:	
Home bound with resource services:	3
Home bound without resource services:	2
Residential:	
Regular hospital (temporary):	1
Speciality hospital (temporary):	0
Institution (permanent):	5
Deceased:	5
Whereabouts unknown:	15

Table 9-9

Selected Discriminant Function Analysis Models Using Prior Child Measures as Predictors of Outcome Status as of Spring 1982 for Children Still in Intervention Program

(Percentage values in diagonal indicate correctly classified subjects)

Predictors: CRIB A & B

N=127*

Into:	More	Expected	Less
From: More	15 55.56		
Expected		31 53.46	
Less			16 38.10

Predictors: CRIB B & Temp

N=118*

Into:	More	Expected	Less
From: More	24 96.00		
Expected		45 83.33	
Less			32 82.05

CRIB A & Temp

N=113

Into:	More	Expected	Less
From: More	12 50.00		
Expected		32 62.75	
Less			21 55.26

* Sample sizes vary due to incomplete data across subjects.

Table 9-10

Discriminant Function Analysis Models Using Prior Child Measures as Predictors of School Placement in Spring 1982 for Children No Longer in Intervention Programs

PREDICTORS: CRIB A & TEMP
N=134

FROM:

24 60.0				
	32 50.8			
		5 71.4		
			5 71.4	
				9 52.9

CRIB B & TEMP
N=134

21 55.3				
	32 50.0			
		3 42.9		
			5 71.4	
				7 38.9

CRIB A & B
N=146

36 83.7				
	52 77.61			
		7 87.5		
			10 100.	
				17 94.4

Discussion and Implications

The findings presented in this report and elsewhere provide support for the application of measures of behavior and temperament with young handicapped children as a means to expand the documentation of child characteristics. The results have indicated that measures of behavioral temperament are sensitive to the functioning of handicapped infants and preschoolers and that assessment in these areas complements the information derived from more traditional measures of developmental maturity. Furthermore, the combination of behavior and temperament measures in multivariate approaches has been found to have potential to predict a clinical index of progress, as well as placement level in terms of degree of restriction.

Implications for further work will proceed in at least two directions, the first involving additional analyses of the data to specify with greater precision, which variables are in fact most effective in documenting child status and which contribute most to prediction of progress. In this regard it is anticipated that some additional data will still be submitted to the project by participating programs, and that additional analyses will be explored beyond the duration of the existing funding period. The analyses reported in the tables and in this report, revealing the differential contribution of CRIB A and B variables and temperament measures as a function of the criterion variable (i.e., outcome status; placement level) suggest that a more precise identification of the predictive utility of individual variables may be feasible and useful. Additional analyses focusing on the specification of behavior and temperament characteristics as a function of unique diagnostic and/or demographic variables is also an area of potential consideration.

The second direction for future efforts lies in extensions of research activities and findings. In this regard several efforts already are implemented and others are being planned. The fact that problems associated with the valid assessment of young handicapped infants find a parallel with profoundly retarded adolescents and adults has led to the initiation of a study to examine the applicability of the CRIB with a residential population characterized as functioning at a nonverbal, nonambulatory level. Ratings of behavior using the CRIB have been made initially and, on a second occasion, a month later, to test for stability of behavior. Follow-up assessments will be made at 6 months and one a year after the initial observation. Results of this study should contribute information about the nature of the CRIB as an instrument to assess the functioning of these populations.

In a related effort proposed with this population, a grant has been approved by the Department of Human Resources of the State of North Carolina to investigate the utility of Goal Attainment Scaling (G.A.S.) as a client program planning and evaluation procedure. The potential value of the G.A.S. procedure in intervention efforts with handicapped populations has been elaborated as one facet of the research activities in the institute (Simeonsson, Huntington & Short, 1982). Systematic trial of its utility will be initiated in the fall of 1982.

As new research initiatives are explored, it is anticipated that issues and findings of the current project will be formulated into research problems. One of these will likely focus on the contribution of family and environmental variables to document outcome of the handicapped child and of the family provided intervention. Efforts similar to the current research, which has demonstrated the contribution of behavior measures to child assessment, should be directed toward the identification of valid measures of the child's family and immediate environment. A related activity based on the above is the prescriptive use of child, family and environment measures to enhance intervention effectiveness. The multivariate strategies followed in the current research project seem applicable to such efforts.

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CHAPTER 10

Curriculum Development and Related Research for Moderately/Severely/Multiply Handicapped Infants

Ken G. Jens and Nancy M. Johnson

Background and Purpose

One major thrust within the Carolina Institute for Research on Early Education for the Handicapped has been the development of a set of curricular materials for use with moderately/severely/multiply handicapped infants and toddlers. While a fairly large number of curricula are available for use with normally developing infants, interventionists have continued to find it difficult to find materials for youngsters who are significantly handicapped and who present very atypical patterns of development.

The goals of the Curriculum Development Project have been to: (1) develop a comprehensive curriculum which is appropriate for mildly as well as moderately/severely/multiply handicapped youngsters functioning within the birth to 24 month developmental range; (2) provide potential curriculum users with a rationale for the format of the curriculum and a clear statement of assumptions underlying the selection of curricular content, and (3) provide data regarding the usability, reliability and effectiveness of the curricular materials when they are used with handicapped youngsters. A secondary purpose of this project has been to continue research in two areas: first, to study child characteristics which might be used to logically determine appropriate levels of curriculum entry and to indicate developmental growth in severely/multiply handicapped young children, and second, to continue research regarding the characteristics of the youngster's environment which affect learning and development.

Literature Reviews and Conceptual Papers

Literature reviews and conceptual papers on a variety of topics relative to curriculum development have been disseminated as a function of this project. These reviews and conceptual papers have related primarily to 1) the characteristics of extant materials and the needs of caregivers, 2) analyses of issues regarding the development of curricular materials for young handicapped children and discussions of models to be used when developing them, 3) assessment problems related to curriculum development and intervention with severely/multiply handicapped young children and 4) impacting upon service providers and personnel preparation programs.

Characteristics of Extant Materials and the Needs of Caregivers

At the time that CIREEH was begun there was considerable demand for curricula which were appropriate for use with handicapped infants and toddlers but, to that time there had been relatively few efforts to produce such materials. Jens, Johnson, Gallagher and Anderson (1977) surveyed curricular materials in use throughout the country in programs for young handicapped children and found that the materials available varied greatly in characteristics as well as the logical or theoretical bases for their development. At that time there were few curricula that would have been considered sufficient in terms of the information and suggestions offered to caretakers, especially as they were concerned with youngsters functioning below one year of age developmentally. While curriculum users indicated a need for more and better developed program materials, they also appeared to be "making do" with materials available, perhaps realizing that service needs are immediate, irrespective of the perceived adequacy of materials available.

That paper concluded that there appeared to be little consensus with regard to what elements of a curriculum are most important, in that areas of emphasis vary greatly from one curriculum to another, that while there are not many materials available for use in developing programs for handicapped infants, a greater problem stemmed from the lack of awareness of available curricula which were available to caregivers and, finally, that many curricula being provided were found lacking conceptually.

Jens, Johnson, Gallagher and O'Donnell (1977) followed up on the previous paper with one that identified problems and offered suggestions regarding curriculum development for severely handicapped infants and toddlers. This paper pointed out that obstacles to curriculum development have been both practical and theoretical and that they were related to the diversity of characteristics presented by severely handicapped infants as well as our understanding of the nature of learning during the developmental years. The paper provided a rationale for future curriculum development efforts, and listed characteristics desirable of curricula for handicapped infants and toddlers.

Bailey, Jens and Johnson (in press) recently completed another review of curricula for handicapped infants. It was noted in this review that a number of changes have apparently occurred over the past five years in that the materials available now have substantially more items available for working with children functioning between the birth and one year level. Comparisons of most widely used curricula were provided on the basis of their theoretical derivations, philosophical bases for intervention and the organization of content material.

Issues Regarding the Development of Materials and Models for Developing Them

A number of papers have been provided which identified issues needing to be dealt with by curriculum developers and program planners and also suggesting models for the development of curricular packages. A general statement regarding the state of the art of curriculum developers concerned with providing materials for young handicapped children was provided by Jens (1979) in a paper entitled Developing Empirically Based Curricula for Severely Handicapped Infants and Toddlers, which was presented at the 87th annual meeting of the American Psychological Association. Jens, Johnson, Gallagher and Anderson (1980) provided a working model for development of curricular materials for young handicapped children and suggested that such materials should (1) be developed on the basis of a normal developmental model with modifications for specific handicaps built in, (2) be validated to the greatest extent possible, (3) provide specific suggestions for facilitating interaction and learning in conjunction with curricular items provided, (4) be designed so that they can be implemented reliably by a wide range of professional and nonprofessional persons in a wide variety of settings and (5) include built-in strategies for data collection and decision making so as to maximize the potential for their appropriate usage.

Several years later Johnson and Jens (in press) pointed out that the idea of providing educational programs for infants, and especially for handicapped infants, is still relatively new. While the federal government has supported numerous demonstration programs through the HCEEP program network, these programs and most others have been aimed at providing services to preschool children between the ages of three and five years. As we have gathered increasing information regarding the developmental pliability of infants, instructional programs for them have gradually increased in number. As this has occurred, the demand for teaching materials has also increased. This paper provided an in-depth discussion of several theoretical bases for the selection of curricular content and the consequences of choosing alternative models. It discussed the implications of alternative models in terms of the selection of teaching and learning strategies, the assessment strategies to be utilized, along with intervention and guidelines for evaluating curricular packages. It pointed out that the ultimate success of any curriculum development endeavor will be determined by the way in which potential users accept curricula and the effect these materials have upon the development of handicapped infants.

Assessment Problems Related to Curriculum Development and Intervention With Severely/Multiply Handicapped Children

Johnson (in press) has pointed out that "one of the major challenges facing interventionists working with young handicapped children is finding accurate, reliable and useful ways to describe the developmental status of these children." This is particularly true as one becomes concerned with the development of curricular materials and the enhancement of intervention for severely/multiply handicapped young children--a population posing very unique and special assessment problems. Concern for the difficulty of assessing cognition in young children who are severely impaired verbally and motorically led Johnson, Jens, Gallagher and Anderson (1980) to begin looking at the relationship between the development of positive affect and cognition in infancy and implications this might have for the developmental assessment of young handicapped children. They reviewed literature relating to four affective behaviors--smiling, laughing, fear (or anxiety), and surprise--which had been studied fairly extensively and each of which had been theoretically or empirically related to cognition in previous studies. Procedures capitalizing on these affective response measures are reasonably free of motor response requirements, and they appear to have potential for assessing the information processing capabilities of young children with atypical motor development. Ideas related to the interactive relationship between cognition and affect and their utility as indices of information processing in handicapped children have been further extended by Jens and Johnson (in press) in an article entitled, "Affective Development: A Window to Cognition in Young Handicapped Children."

Johnson (in press) has pointed out that three basic paradigms have been utilized for assessing development in children under three years of age. These are norm referenced standardized psychological tests, criterion referenced tests and ordinal scales of development. She pointed out the utility and difficulties associated with each of these paradigms and suggested that any assessment paradigm should be evaluated for the validity of its underlying assumptions and its usefulness for particular objectives at any given time. Johnson also pointed out that the basic objectives of assessment within intervention settings are generally (a) the diagnosis or prediction of future developmental status, (b) the identification of appropriate intervention goals and (c) the evaluation of child progress or program effectiveness. At any point in time one, two or all three of these objectives may be the target of assessment, and before assessment procedures are chosen, the objectives specific to that assessment should be identified and each procedure evaluated critically against those objectives.

Jens and O'Donnell (in press) have suggested that a potential gap exists between the available information regarding development and practitioners' willingness to use this information for decision making. They suggested the use of an "as if" model wherein one approaches the scientific literature on development "as if" it had in fact been validated, if the information provided appears to be useful for assessment and intervention purposes. This would of course be done with caution in that many of the decisions made would eventually have to be reassessed and perhaps even recognized as having been wrong. It would, though, allow persons to utilize developmental information more immediately than it is currently being used, and it would put that information and intervention efforts in the context of constant evaluation. Above all, it would make substantially more information available to practitioners than what is available through the variety of packaged and standardized formats. It would also put considerable demands upon them in terms both of maintaining awareness of the professional literature available to them and judging its applicability to children with whom they work.

Impacting Upon Service Providers and Personnel Preparation Program

As one becomes involved in the development of materials for use in intervention programs with young severely/multiply handicapped children it becomes obvious that there are other variables impacting upon these programs which also must be addressed. One of the most important of these has to do with the development of personnel preparation programs which will train personnel to teach young severely handicapped children and the development of certification standards to be utilized by the states in certifying teachers for this population. Jens et al. (1980) pointed out that personnel preparation programs cannot exist independent of the populations with whom their students will be trained to work, nor can these programs be adequately developed without planned utilization of resources, both within universities and the larger communities which they serve. Guidelines were provided wherein colleges and universities initiating such training programs could logically provide evidence of 1) need for the program, 2) adequacy of their resources to develop and maintain the program, 3) personnel resources and reasonable scope and quality of instructional content, 4) an understanding and delineation of program limitations and 5) a process for continuous program evaluation. It was suggested that programs must project training needs on the basis of currently available data, but that these data must reflect the effectiveness of the program as it has operated, show its flexibility to meet immediate and unplanned needs regarding training, population changes, and service need changes, and then project its plans to meet identified training and service needs of the future.

In a related paper Jens et al. (1979) delineated a number of complex questions and issues relating to the development, implementation and monitoring of personnel preparation programs. One of the issues identified was that of certification of teaching personnel and in particular, the relationship between the development of program content or target competencies and certification requirements. Some of the more pertinent issues surrounding certification of personnel to work with severely/ multiply handicapped young children were identified as a) the identification of competencies needed for teaching this population, b) the identification of program content through which the acquisition of competencies be achieved, c) uncovering the relationship between the child, program needs, and state certification requirements, and d) the need for reciprocity between states for certification for professional teaching personnel.

Problems relative to defining the severely handicapped population, a necessity for determining who will be included in programs, was discussed, as was the current status of certification of personnel working with the severely handicapped in a variety of states. A case was then made for certification of personnel working with severely/multiply handicapped young children and six areas of expertise thought to be critical to teachers of this population were presented. In addition, a model for certification was presented which put services for all handicapped children into a matrix based on an age/school level dimension and a severity of handicap dimension.

Recommendations from this paper regarding the definition of severely handicapped children for school purposes, as well as the development of certification processes, have been implemented in several states.

Curriculum Development

Rationale

Bailey, Jens and Johnson (in press) have pointed out that a new flurry of activity directed at curriculum development arises whenever educators are charged with teaching new subject matter or educating a new population. This project responded to a new impetus to provide educational programs for severely/multiply handicapped young children and an associated need for curricular materials.

Procedures

The original curriculum development proposal called for the development of a curriculum for moderately/severely/multiply handicapped infants that was essentially an expansion and modification of a well validated curriculum for normally developing children. It was felt that this approach would be advantageous in that it would maximize the possibility of integrating handicapped and normal children in preschool settings.

While the goal of providing integrated educational services for handicapped and normal children has been maintained, the approach to curriculum development shifted as the authors became aware of the problems inherent in providing sufficient modifications to meet the needs of youngsters with a variety of atypical developmental patterns. Subsequent efforts focused on defining a relatively comprehensive list of developmental content and organizing it in such a way that specific handicapping conditions could be accommodated by adding or deleting sections without altering long-term educational objectives and without the necessity of generating a variety of modifications.

Two major factors were considered in determining a strategy for curriculum development: 1) curriculum development proceeds best from well defined tasks which are sequential in nature, wherein one task provides a direct building block for the next task to be accomplished; and 2) a curriculum that will be used with severely/multiply/handicapped children must begin with the assumption that most of these children will never achieve "normalcy," although each must be given the chance to develop his fullest potential. Thus, while "normal" skills serve as the foundation of the curriculum, skills are also included which give every child an opportunity to develop an alternative route to desired adaptive goals, particularly those related to cognition and communication. The strategy selected was basically one of generating a comprehensive list of skills or competencies normally mastered within the first two years of life, dividing these competencies into logical sequences for learning, and then developing additional sequences to serve as alternative communication and cognitive strategies for children with specific sensory or motor handicaps.

Since the birth to twelve month developmental period has remained relatively neglected in curriculum development, since many severely handicapped youngsters remain in the developmental period for all of their preschool years, and because curricula for this period should serve as the foundation for intervention with older infants, initial efforts were focused on this developmental period. Then, on the advice of the CIREEH National Advisory Committee, a decision was made to extend the curriculum only to the 24 month developmental level, rather than to 36 months, as initially proposed. The rationale for this change was that relatively few severely handicapped preschool children will develop beyond the 24 month level and, if they do, curricula developed for normal and high-risk preschool children are likely to be appropriate for use with them.

The delineation of items to be included within the curriculum began with a survey of existing curriculum materials for both at-risk and handicapped infants and toddlers (Jens, Johnson, Gallagher & Anderson, 1977). This survey provided information regarding the variety of developmental items that were included in various materials, as well as widely differing formats for presenting items to potential curriculum users.

Information obtained from the survey of these materials as well as the literature on both normal and abnormal development resulted in the compilation of a list of developmental items which were then screened for appropriateness and comprehensiveness by interventionists on an interdisciplinary team: physical and occupational therapists, a language specialist, an educator, and a psychologist. These were then organized into "logical teaching sequences," i.e., sequences in which each skill builds directly upon the previous skill in the sequence. Once this was done, each item was considered individually, and information written regarding the position in which a child could be taught the skill inherent in each item, the materials necessary, the instructional procedures to be utilized, and criterion measures to be used in determining when objectives had been met. Items were also task analyzed for features which would limit the interaction of children with physical handicaps, visual handicaps, and those who did not develop verbal language. Special instructional notes and cautions were attached to items when appropriate and additional procedures were provided to facilitate instruction for these children as necessary.

The original birth to one-year curriculum was developed and field tested with 19 instructional areas. The revised birth to two-year curriculum encompasses 24 instructional areas.

Field testing. Initial curriculum development efforts resulted in a curriculum for use with handicapped infants and young children functioning in the birth to one-year developmental age range. This curriculum was distributed to some 70 programs for review and was field tested in 23 programs throughout the United States. In addition, 400 copies were sold to programs providing intervention to young severely handicapped children.

Data collected from field testing are being used to assess two attributes of the curriculum: 1) its effectiveness in promoting child progress, and 2) its "usability"--the extent to which it increases the caretaker's understanding of and ability to plan programs for handicapped youngsters. In addition, data were collected to determine both procedural and scoring reliability when the birth to 12 month items of the curriculum were being used.

Information received from both field testers and people who reviewed the curriculum to date indicate that they are generally pleased with the format and the content and that the curriculum package did in fact fill a substantial need. Several programs provided regular feedback regarding the use of the curriculum by a variety of professionals, paraprofessionals and parents with children having differing handicaps. All of this feedback was considered in the rewriting of the first year curriculum and the incorporation of curriculum items from the 12 through the 24 month level. This resulted in substantial changes. Some instructional areas were divided and reorganized, items were deleted, other items were generated, and the data collection procedures modified.

One area of field testing, related to usage of the curriculum, has provided enough data so that perceptions of interventionists regarding its usability can be summarized. Data from personnel in the 23 programs involved in initial field testing indicated the following:

1. The curriculum appears to be comprehensive in covering the significant developmental areas of infancy (94% agreement);

2. The selected curriculum sequences "make sense" as bases for intervention (94% agreement);

3. It provides a good assessment of strengths and weaknesses (92% agreement);

4. Curriculum items are easily understood (100% agreement);

5. Data collection procedures are clearly outlined (89% agreement); and

6. There is no need for substantial changes in the curriculum--it is broadly applicable to children functionning within the developmental range which it covers (90% agreement).

Field test data speaking to the effectiveness of the curriculum in promoting child progress will be analyzed after all field testing is completed and the data will be provided as a supplement to the published curriculum.

Research on Child Characteristics

The past decade has seen substantial changes in both attitudes and procedures affecting the education and treatment of young handicapped children. It is now acknowledged that early intervention is not a luxury to be afforded only when excessive funds are available but, rather, it is a prerequisite for maximizing the development of children born with handicapping conditions, as well as those born at-risk for such condition.

Despite enthusiasm on the part of program directors responsible for implementing these new programs, they are faced with a variety of very real fiscal, conceptual and procedural problems at the current time. One of the greatest of these conceptual and procedural problems has to do with how programs will assess and monitor development in young children who are handicapped to the point of not being able to call upon the normal motor and verbal responses required by the tests traditionally used to assess infant and toddler cognition. Tests have provided the criteria whereby we determine eligibility for services, the nature of services appropriate for given children, and the effectiveness of services. We also know, though, that research has repeatedly indicated that conventional tests of infant behavior are less than reliable predictors of subsequent behavior.

Several basic assumptions appear to underlie the use of traditional assessment instruments. The first assumption is that intellectual ability is fairly static across age levels. Research studies investigating the relationship between infant performance at varying ages, however, have indicated minimal correlations between ages, suggesting that such functioning across ages is not merely a linear process.

Research efforts associated with the curriculum development project have focused on evaluating the usefulness of various measures of affective development as alternative (or supplementary) indicators of cognitive development in severely/multiply handicapped youngsters. A study entitled "Positive Affect in Multiply Handicapped Infants: Its Relationship to Developmental Age, Temperament, Physical Status and Setting" (R. J. Gallagher, 1979) showed that the development of smiling and laughter is developmentally predictable among handicapped youngsters. The onset of both are somewhat delayed, relative to their appearances in normal youngsters, as would be expected. This study also showed that developmentally older handicapped children can be differentiated from younger children on the basis of the amount of smiling and laughter offered to differing kinds of stimuli at different ages.

In addition to continuing to collect data on a small sample of handicapped youngsters, a pilot study of twenty normal 6 and 12 month old infants was done in an effort to determine the strength of the "smile procedure" in identifying cognitive differences in youngsters of the same age. In this small sample the total number of smiles and laughs emitted by youngsters was found to be highly correlated with mental development as measured by the Bayley Scales of Infant Development ($r=.95$, $p<0.01$) (Roer, Johnson & Jens, 1981).

Creekmore (1979) studied "the relationship between the development of visual preference and selected affective responses in normal infants." Because visual preference markers were being sought at very early age levels (i.e. one, two, three and six months), significant developmental changes in affective behavior were not found and thus the relationship sought within this study remained nonsignificant. The study did assist in preparing for continued visual preference and recognition memory studies which may be more helpful for assessing young handicapped children.

Anderson (1980) studied positive and negative affective responses as developmental markers in moderately and severely handicapped infants and toddlers. This study utilized the smile/laugh response as one independent variable. It also investigated utility of negative affect in the form of fear on the visual cliff as a dependent variable. This methodology did not prove very useful for providing developmental markers, in that 85% of the infants assessed responded neutrally to both the shallow and deep side of the cliff. Only 15% of the youngsters tested showed differential behavioral responses which could be used to mark the development of depth perception and the fear response. In addition, the data are complicated by the fact that the fear response is both difficult to measure and is associated with the onset of ambulation. Thus, this affective measure does not appear to be useful as an indicator of cognitive growth, per se.

Gallagher, Jens, and O'Donnell (in press) reported on the relationship between the physical status of handicapped youngsters and their ability to demonstrate positive affect. They pointed out that, as physical impairment increases in severity, a corresponding decrease is shown in the infant's ability to smile and laugh. Thus, while smiling and laughter may be important indices of information processing, it is also important to recognize the limitations imposed by physically handicapping conditions on a child's ability to emit these responses.

A study of the social networks and family environment of mothers of multiply/severely handicapped infants (Sauer, 1980) was facilitated through the curriculum development project. This study assessed individuals' intimate social networks according to their structure and function, and family social climates as perceived by family members within families having handicapped children, as well as families not having handicapped children. Results of the study were surprising in that it was found that families with handicapped young children do not differ from those whose children are not handicapped in terms of their social climate and the extensiveness of their social networks. Their support networks did include more professionals involved in the care of their children, however.

Assessment Instruments

While it was not the intention of this project to develop any assessment instruments per se, two were developed on the basis of need generated during the curriculum development project. First, the developmental progress chart included with the curriculum has become popular as an assessment tool in programs where the curriculum has been field tested and otherwise used (Johnson, Jens, & Attermeier, 1982). Because of this, and because it is essential to have an instrument which is easy to use in assessing developmental behavior before entering a curriculum, provisions are being made to develop an assessment package which will stand alone, but which is to be used with the Carolina Curriculum for Handicapped Infants.

Another assessment instrument, the physical status research form (Attermeier, Gallagher, and Anderson, 1979), has continued to be used in studies being done with severely/multiply handicapped infants. This instrument represents an attempt to develop a procedure for quantifying physical status (i.e., muscle tone) so that physical status can be more objectively related to other developmental measures in the study of handicapped youngsters. Neither of these instruments has been subjected to extensive reliablilty and validity studies, steps that will be necessary prior to their distribution as independent assessment measures.

Discussion and Recommendations

The curriculum development project has produced a curriculum for moderately/severely/multiply handicapped children functioning within the 0-24 month developmental period. The curriculum has been enthusiastically received by interventionists across the country, although the field test experiences suggests that intervention programs will generally be more comfortable with any curriculum when allowed to modify it to fit their particular biases and service model, than when required to use it strictly as written. According to statements of users, the most unique aspect of the Carolina Curriculum for Handicapped Infants is its organization into many instructional areas, providing both a better understanding of how development proceeds in each, and a means of assessing youngsters with markedly atypical development.

Because of the apparent usefulness of the curriculum entry assessment and progress chart in understanding a child's unique developmental patterns, it is likely that it will be used as an independent assessment procedure even in the absence of adequate reliability and validity data. Thus, it is recommended that such data be collected through continued study of handicapped young children and a representative sample of normal children.

A second area meriting particular attention is the evaluation of the curriculum for use with severely and profoundly handicapped older children. Many public school programs serving children between 6 and 21 years of age have requested the curriculum. The authors have major reservations about its applicability to this population, but have no data to support or reject such reservations. Since the curriculum will probably be used in such settings, whether or not the data exist to support such use, it will be important to provide those data.

Finally, if the field test data on the 0-12 month curriculum are a good indication, a six month field test period is inadequate to allow an evaluation of curriculum effectiveness, vis a vis child progress data in severely and multiply handicapped youngsters. Yet, most programs are unwilling to assume responsibility for longer data collection periods. In order to more thoroughly evaluate the effectiveness of the curriculum and to understand which instructional areas are most amenable to intervention efforts, it will be necessary to follow a sample of children over at least a two year period, perhaps using less time-consuming data collection procedures.

Some of the research on child characteristics that was begun in the curriculum development project is being continued through support from other sources. The study of alternative forms of assessing cognition in the handicapped infant population is clearly merited, since many kinds of handicaps masquerade as mental retardation in the first years of life. Research must continue in this area, but considering the nature of the predictive problems in infancy, it is critical that such research be supported on a longitudinal basis.

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(CIREEH products, cited in this section, are referenced in the Products List in Chapter 13.)

CHAPTER 11

Project CARE

Craig T. Ramey, Joseph J. Sparling, Barbara H. Wasik
and Donna Bryant

Background and Purpose

Project CARE was designed specifically to compare center-based and home-based early intervention programs as well as to examine the processes of development that might be affected in both mothers and children who were involved in the programs. Children entered the study as infants and have been followed through the age of two. As of June 1982, the youngest child was 27 months old and the oldest child had just turned 4 years old. This first section will describe the rationale for conducting such a longitudinal study.

From the mid-1960's to the 1980's, programs for prevention of mild retardation have varied in the target of intervention, the form of program delivery, and the content of the curriculum. Eighteen exemplary prevention-oriented programs were reviewed recently by Ramey, Sparling, Bryant, and Wasik (in press). The programs all began during the first two years of life and focused on infants at risk for mild retardation.

The targets for intervention typically have been the infant and the mother. The major program delivery forms have included educational home visitation (e.g., Gutelius, Kirsch, MacDonald, Brooks, & McErlean, 1977; Gordon & Guinagh, 1978; Schaefer & Aaronson, 1977), group educational day care (e.g., Caldwell & Richmond, 1968; Robinson & Robinson, 1971), home visit-day care combinations (e.g., Ramey & Haskins, 1981), and parent group sessions (e.g., Badger, 1981). In addition, some programs have included job training for parents (e.g., Garber & Heber, 1977), and medical care for children (e.g., Ramey & Haskins, 1981). Curriculum content of these programs is difficult to divide into distinct categories because it has varied across a wide spectrum within programs and included content as diverse as sensorimotor infant exercises (e.g., Painter, 1971), parent teaching styles (e.g., Gordon & Guinagh, 1978), and problem solving skills (e.g., Ramey, Sparling, & Wasik, 1981).

Most of these projects had small sample sizes which may limit the generality of their results. Further, few studies have been replicated. Depending on the manner in which subjects were selected, some studies had a problem of self-selection initially or of attrition at a later point. The majority of the prevention-oriented studies included a test-only comparison group, whether randomly assigned or selected from another sample and matched with the subjects receiving treatment. Randomization to treatment and control groups is the most powerful experimental procedure to assure initial equivalence of groups; however, very few programs have used this critical design feature.

Experiences from these programs allow us tentatively to answer questions about the content of the curriculum and its extensiveness, the target of the intervention effort (parent, child, or both), how early to begin, and the outcome to be expected from such preventive intervention. The purpose of Project CARE was to address some of the major unsolved issues about these intervention programs including: What kinds of programs are the most effective? What are the mechanisms by which the intervention effects are achieved? Home programs which have focused on parent training have presumed, but not demonstrated, that they have significantly affected parenting style and that the altered style was the causal agent in the treated children's progress. Further, there is, at present, no evidence concerning whether the approach of day care education plus family education can have more powerful intellectual effects than family education alone. To address these issues, our project's major activity has been the implementation and conduct of an early intervention program called Project CARE (Carolina Approach to Responsive Education).

Methods

Subjects. The first cohort of 25 high-risk families and their 27 infants (2 sets of twins) entered into the program in November, 1978. A second cohort of 38 infants was admitted a year later. The families were matched in sets by the High-Risk Index (Ramey & Smith, 1977) and randomly assigned to one of three experimental groups: Family Education Alone, Day Care plus Family Education, or a Control group. Restriction of space in the infant nursery limited the number of high-risk families to 16 in the Day Care plus Family Education group; 25 and 23 families respectively were randomly assigned to the Family Education and Control groups. Through age 2, attrition among the high-risk subjects was 3%; one infant died at 3 months of age (crib death) and one child moved out of town with his family at 11 months of age.

In addition to these 63 high-risk families, 18 more advantaged or low-risk families were involved in the program, 13 in the first cohort and 5 in the second cohort. These families were included to provide racial and economic diversity in the day care program and to have a comparison group of non high-risk families. Attrition among the non high-risk families, through age 2, was 17%; 2 families moved and 1 withdrew from the project.

Table 11-1 presents some demographic characteristics of the high-risk sample. Random assignment did indeed result in three groups of high-risk families that were remarkably similar in initial characteristics.

Treatment. The content and the service procedures of the day-care program in effect in Project CARE were derived from its predecessor at the Frank Porter Graham Child Development Center known as the Carolina Abecedarian Project. Infants were enrolled prior to three months of age and participated for 6-9 hours per day for approximately 50 weeks a year.

The primary curriculum resources for the first three years, Infant Learningames and Learningames for the First Three Years (Sparling & Lewis, 1978; 1979) were designed to allow the daycare professionals to create an individualized experience for each child through a recurring cycle of observation, prescription teaching, further observation, and revised prescription. The activities stimulate both the social/emotional domain and the intellectual/creative domain. The treatment, of course, encompassed all of the service and caring procedures which occur in the day care center.

The plan for the Family Education component of Project CARE and its rationale was described by Ramey, Sparling, and Wasik (1981). The principal method of parent education and information dissemination was through person-to-person contact with the para-professional home visitor every 1.5 weeks. Approximately 98% of the visits were with the mother, although the fathers and grandparents were, on a few occasions the participants. Scheduling of visits was done during one visit for the next (12%), by personal contact at the day-care center (26%), by telephone (53%), by notes sent with the transportation officer (9%), and sometimes in the case of younger mothers, through older relatives. For high-risk mothers 1.4 scheduling contacts were needed to accomplish one visit.

The focus of the home visit in a majority of instances (78%) was a child learning activity which acted as an entree to an exchange of information on child development, problem solving, or the teaching of parenting skills. These visits were typically about an hour (75% were between 30 and 60 minutes) in the parents' home, although other kinds of contacts were used when necessary to accommodate the parent's scheduling needs.

Each family in the program was given the looseleaf notebook Infant Learningames (Sparling & Lewis, 1978) which contains an index

Table 11-1

Demographic Characteristics of Project CARE Families at Time of Child's Birth

	Daycare Plus Family Education (n=16)	Family Education (n=25)[1]	Control (n=23)
Age of Mother	22	20	22
Age of Father	25	24	24
Education of Mother	10.9	10.6	11.3
Education of Father	11.4	11.1	10.9
Mother's WAIS			
Full scale	86.8	86.8	87.5
Verbal	84.8	85.8	85.7
Performance	90.9	90.0	92.4
High Risk Index	20.0	21.0	20.3
Income[2]			
Mother's	$4079 (n=8)	$2796 (n=14)	$2641 (n=10)
Family's	$5173 (n=14)	$7514 (n=23)	$6388 (n=23)
% single, never married	56%	84%	70%
% single, separated, divorced, combined	75%	84%	83%
Characteristics of Target Child			
% boys	56%	63%	65%
% black	94%	96%	83%
Number of siblings	.6	.8	.6

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[1] There are 2 sets of twins in the Family Education group for a total of 25 mothers and 27 children in the group.

[2] Mothers and/or families with no incomes or no reported incomes were not included.

of learning activities, developmental information, record keeping materials, and parent skills information. The 100 activity cards designed to be included in the notebook were added one-by-one, in some instances, as the games or activities were demonstrated, and for other parents a large cluster at a time were added, depending on their interest. Because each activity was written at two levels, this notebook was used with both the professionals in the day care center and with parents.

In addition to the visits in the households, the visitors periodically gathered groups of parents at the day care center or another location to provide some special information and to encourage discussion of child development in a social atmosphere. These gatherings, which constituted 13% of the total contacts, were planned to provide for delivery of information which would have been difficult, if not impossible, to take to individual homes. Originally planned as meetings with just two or three parents, they evolved into larger groups when other parents in the program asked to attend. The unexpected benefit was the growth of a spirit of unity among many of the program participants which otherwise may not have occurred.

A basic part of the family education program was a curriculum designed to teach parents problem solving skills. The rationale for such training was based upon the idea that problem solving is an ability which is necessary for effective parenting and the handling of day-to-day problems, and that this ability could be enhanced by specific training. To implement the parent training, home visitors were taught to help the mothers increase their problem solving skills. The training consisted of teaching the mother the steps of a problem solving model and using this model to deal with ongoing concerns of the mothers. The steps are problem identification, generation of solutions, evaluation of solutions, decision making, implementation, and evaluation of the outcome.

In weekly meetings the home visitors were trained to help parents learn problem solving skills. These weekly meetings served as an opportunity for the home visitors to discuss and receive feedback on their interactions or concerns with individual mothers. A manual on the problem solving curriculum was prepared (Wasik, 1982), containing all the training materials, parent handouts, and rating scales used in the problem solving training.

Instruments. Our research design required longitudinal assessments of children's cognitive and socioemotional status as well as parental attitudes, knowledge, skills, and interactional styles with their children. Table 11-2 provides a summary of the assessment schedule in each of these domains and specifies in terse labels the

Table 11-2

FPG Preschool Data Collection Summary

	Birth	6-month	12-month	18-month	20-month	24-month	30-month	36-month	42-month	48-month	60-month
tellectual velopment	Mother IQ (WAIS)	Bayley	Bayley	Bayley		Bayley Stanford-Binet	McCarthy	Stanford-Binet	McCarthy	Stanford-Binet	WPPSI
mperament		Infant Behavior Record (IBR) Infant Temperament Scale	IBR Toddler Temperament Scale	IBR		IBR Kohn and Rosman	Kohn and Rosman Toddler Temperament Scale	Kohn and Rosman	Kohn and Rosman	Kohn and Rosman	Kohn and Rosman EASI
rent-Child nteraction		Videotaped mother-child interaction free play* Videotaped teaching task*	Mother-child Interaction* Teaching Task* Strange Situation Videotape	Teaching Task*	Mother-child Interaction*			Mother-Child Interaction* Teaching Task*			Mother-Child Interaction* Teaching Task*
me nvironment	Demographic Information	Caldwell's Home Stimulation Inventory	Home Stimulation	Home Stimulation Demographic Data			Home Stimulation Demographic Data	Holmes-Rahe Life Change Scale	Home Stimulation Demographic Data		Home Stimulation Demographic Data
arental ttitudes		Parent Attitude Research Instrument (PARI) Rotter		PARI Rotter	Inventory of Caregiver's Child Development Values and Concepts*		Parent Evaluation of Program*	Attitude Questionnaire*			Attitude Questionnaire* Evaluation of Program*
arent Skill nowledge and upport Systems			Community Interaction Checklists (6) Supports* Interview	Parent Problem Solving Instrument*		Community Interaction Checklists (6) Supports Interview*	Knowledge of Infant Development Inventory*				Supports Interview* Community Interaction Checklists (6)
iological evelopment	Pregnancy and birth data	Growth Measures**	Growth Measures**	Growth Measures**		Growth Measures**		Growth Measures**		Growth Measures**	Growth Measures**

*Indicates a new instrument developed by FPG Investigators

**Growth measures include daily health records procedures which are defined in Appendix A. In general we chose to use assessment instruments in the various domains of measurement which either had been previously developed and standardized by other researchers (e.g. the Stanford-Binet Scales) or which had been developed and already reported in the scientific literature (e.g. the coding procedures for mother-child interactions developed by Farran & Haskins, 1980).

Intellectual development of the children was assessed by the Bayley Scales of Infant Development (6, 12, 18, and 24 months), the Stanford-Binet (24, 36, and 48 months), and at later ages by the McCarthy (42 and 54 months). Measures of the home environments were taken with Caldwell's Inventory of Home Stimulation (HOME) (6, 12, 18, 30, and 42 months). Maternal attitudes were measured with Emmerich's version of Schaefer and Bell's Parent Attitude Research Instrument, the Rotter Internality-Externality Scale (6, 18, and 36 months), and the Frank Porter Graham Intake Interview.

Mother-child interactions were assessed in a standard "living room" setting where the mother and child were left alone with toys, books, and magazines for 20 minutes. Videotapes of behavior were coded using Farran and Haskins' (1977) Modified Form of the Reciprocal Control Category System (6, 12, 20, and 36 months). The 6- and 12-month tapes have been coded to date. The coding focused on parent behaviors such as directiveness, responsiveness, and proximity to the child, and the amount of time playing together, reading together, observing the child and being unoccupied. Child behaviors were coded in a similar fashion.

The Problem Checklist and Parent Problem Solving Inventory (Wasik, Bryant, & Fishbein, 1982) were two measures used to broaden our knowledge of family functioning. To assess the range of problems that families might have, a problem identification procedure was developed. The assessment was a half-hour interview with the mother that included a Problem Checklist. The Checklist contained problems concerning childrearing, income, housing, employment, personal relationships, health, and transportation. It also included the Holmes-Rahe Schedule of Recent Experiences, a measure of stress. This interview was conducted with mothers when the infants reached the age of three months. These data provided an initial baseline of the number and types of problems that concerned the families.

In addition, to study the ability to use means-ends thinking in solving family problems, Spivack's means-ends problem situations were adapted to create the Parent Problem Solving Inventory, given to mothers when their infants were 18 months old. Problems relating to childrearing were chosen as the specific area of family functioning on which to focus. Mothers' responses to the problem situations were recorded and they were then asked to choose the best possible alternative from a list of alternative solutions. This instrument seemed better for our purposes than Spivack's original instrument because it was specifically geared to childrearing, the area targeted by our intervention programs.

In the assessment schedule in Table 11-2 new instruments developed as part of Project CARE are noted with an asterisk. It should also be noted that the development of several of these instruments and the costs of collecting data using them was supported by a grant to Drs. Sparling and Ramey from the Administration for Children, Youth, and Families (ACYF). These new instruments include the Parent Evaluation of Program Questionnaire, Inventory of Caregivers' Child Development Values and Concepts (Gowen & Gustafson, 1980), Supports Interview, and Knowledge of Infant Development Inventory. These instruments are also briefly described in Appendix A.

Results

Three broad categories of results will be presented in this section. Project CARE collected a large amount of program implementation data which will be summarized first. Second, results will be presented from standardized tests of intellectual development, the typical outcome measures, along with some other child characteristics. Third, selected data will be presented from parent and family variables --variables that measure psychological mechanisms through which parent education might be affecting the childrens' intellectual development.

Program implementation. The project collected a larger amount of program implementation data than is typical for most intervention projects. We conceptualized the intervention program as more than the "content" of the curriculum. Thus, it was important to collect data on the process by which the program was implemented and the interactions with the individuals involved. We have used these various data sources and their interactions to provide on-going internal feedback or guidance for the program.

At its most basic level, implementation data in this project consisted of duration of child attendance in day care and frequency of home visits to parents. The two treatment groups received equal numbers of visits, with the Parent Education Plus Day Care group receiving an average of 2.65 visits per month and the Parent Education Alone group receiving an average of 2.53 visits per month (Sparling, 1981).

Beyond the frequency counts, somewhat more subtle data were collected to describe the curriculum in action. These data included reports on the success of visits, scheduling difficulties, the participants of each visit, and the main content of each visit. A periodic audit of many of these variables was provided to the visitors as computer-generated histograms. Similar histograms were provided family-by-family to the visitors. This allowed the visitors to periodically reassess the delivery of the program and to adjust it so that families were treated equitably. Even with this feedback as guidance, the program was delivered with greater success to some families than to others.

Figure 11-1 is a histogram summarizing the 3,214 home visits that were on file at the end of December, 1981. These data, along with those mentioned in the treatment section, are important for two reasons. First, they provide an overall summary of what the "home visit" program actually was--what efforts were involved in completing visits, where visits occurred, who participated in the visits, and what topic or activity was presented. Intervention programs often describe the intended treatment, but seldom collect implementation data. We hope that these data document Project CARE's intervention and provide for future intervention efforts a model of data collection that is relatively easily obtained.

Child outcome measures. Evidence for the effectiveness of the Daycare plus Family Education program is presented in Figure 2. This figure contains the mean Bayley MDI scores for the three high-risk treatment groups at 6, 12, 18, and 24 months of age.

Inspection of Figure 11-2 reveals some trends that are theoretically interesting and practically important. At the first assessment occasion (6 months) the three groups have mean MDI performances which are quite similar. This finding is, of course, expected, because random assignment should have made the groups initially comparable and no data exist to predict that early intervention should have a beneficial impact by this early period. However, by 12 months of age the Daycare plus Family Education Group is above the performance of the other two groups, which appear quite similar to one another. This trend continues at 18 months and in the completed 24-month data set. At 24 months the most intensively treated group has a mean Bayley MDI of 114 compared to a control group mean of 97 and a Family Education Alone mean of 92. One way analysis of variance on these scores indicates that the groups differ significantly ($F_{(2,56)} = 14.12$, $p < .0001$). Comparisons by pair-wise t-tests between groups show that the Daycare Plus Family Education Group exceeds both of the other two groups ($t_{s(35)} \geq 3.86$, $p_s < .001$). Family Education Alone does not differ significantly from the Control group. That the control group's developmental trend is downward over the first two years substantiates the initial risk status of the group and replicates previous findings by Garber and Heber,

Figure 11-1

Description of 3214 Home Visits

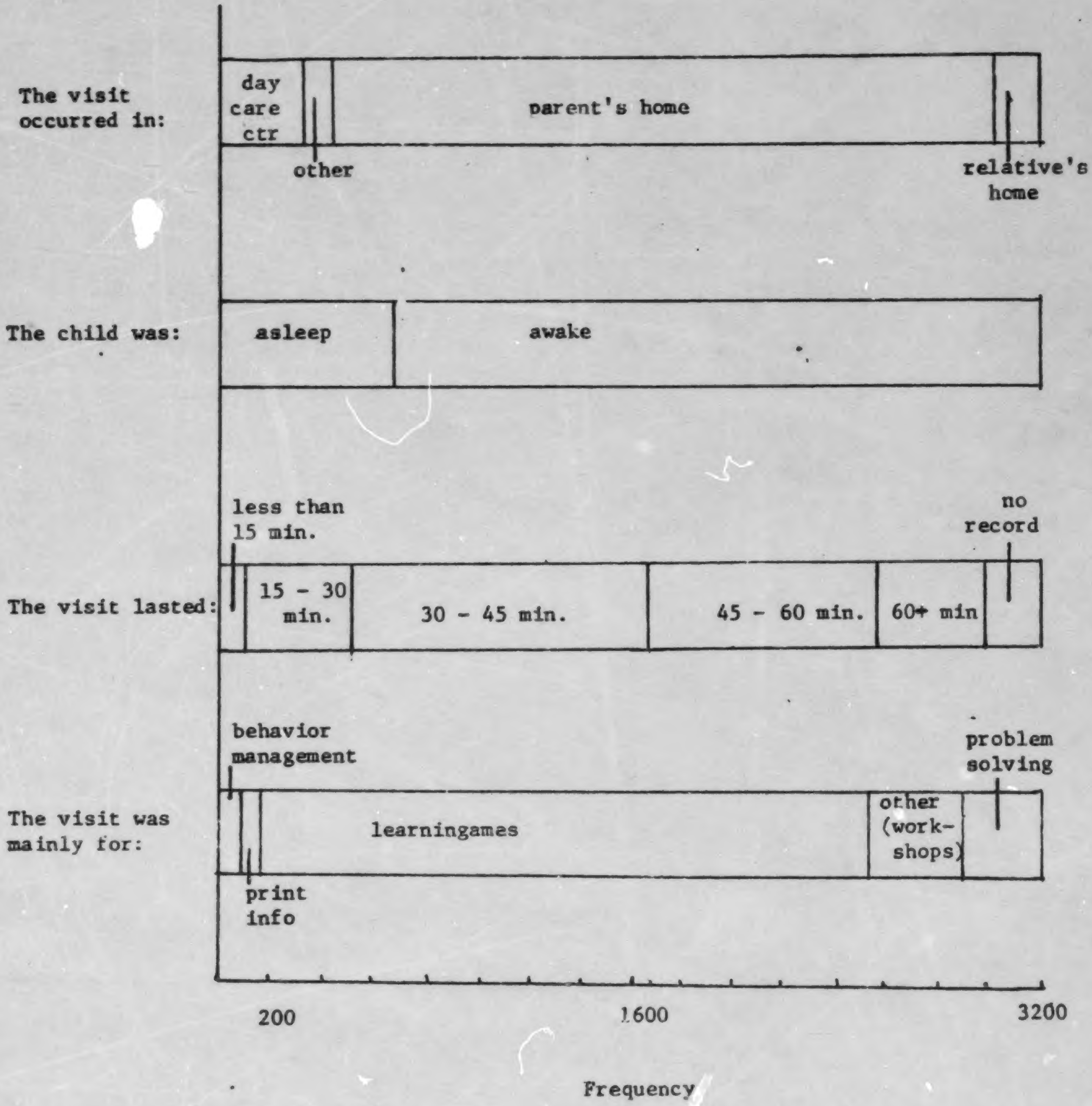
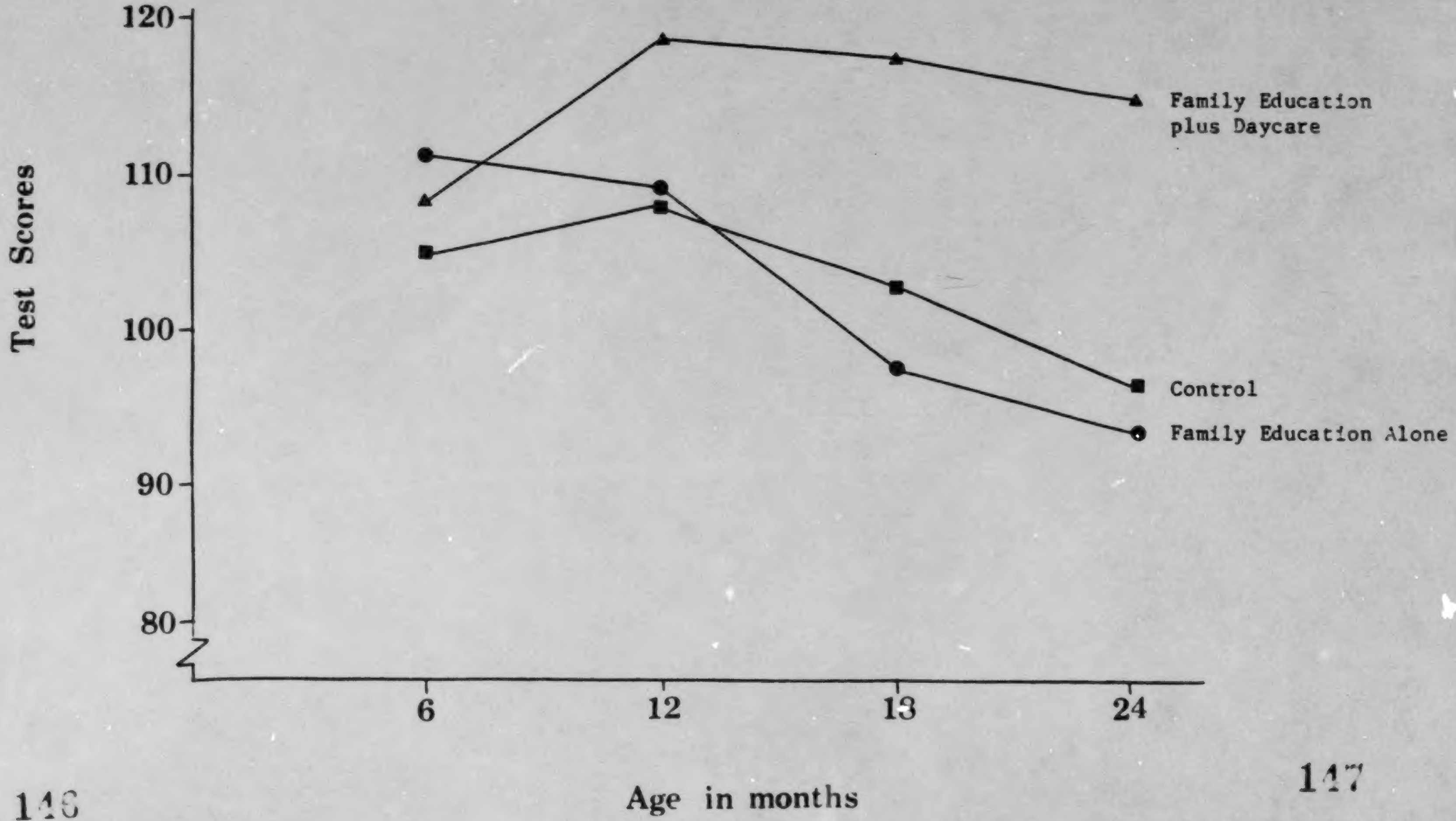


Figure 11-2

Mean Bayley MDI Scores

for High Risk Children in Project CARE



(1977); Ramey and Haskins, (1981); Gutelius et al., (1972); and Gordon and Guinagh, (1978).

However, the similar decline in the Family Education Only group was certainly not predicted and is indeed problematic. One possible explanation is that because that treatment condition is less intense and requires family participation, it will have to occur for longer periods of time before its effects are known. It is noteworthy that results from the Gordon Florida project (which is the most directly comparable project to our Family Education only component) are strikingly similar to our own findings. In fact, in the Gordon project the Control group outscored the experimental group intellectually at two years and did not show significant positive effects until 36 months. Therefore, it seems particularly desirable that these findings for our Family Education Only group be pursued because of their obvious public policy implications for the education of high-risk infants.

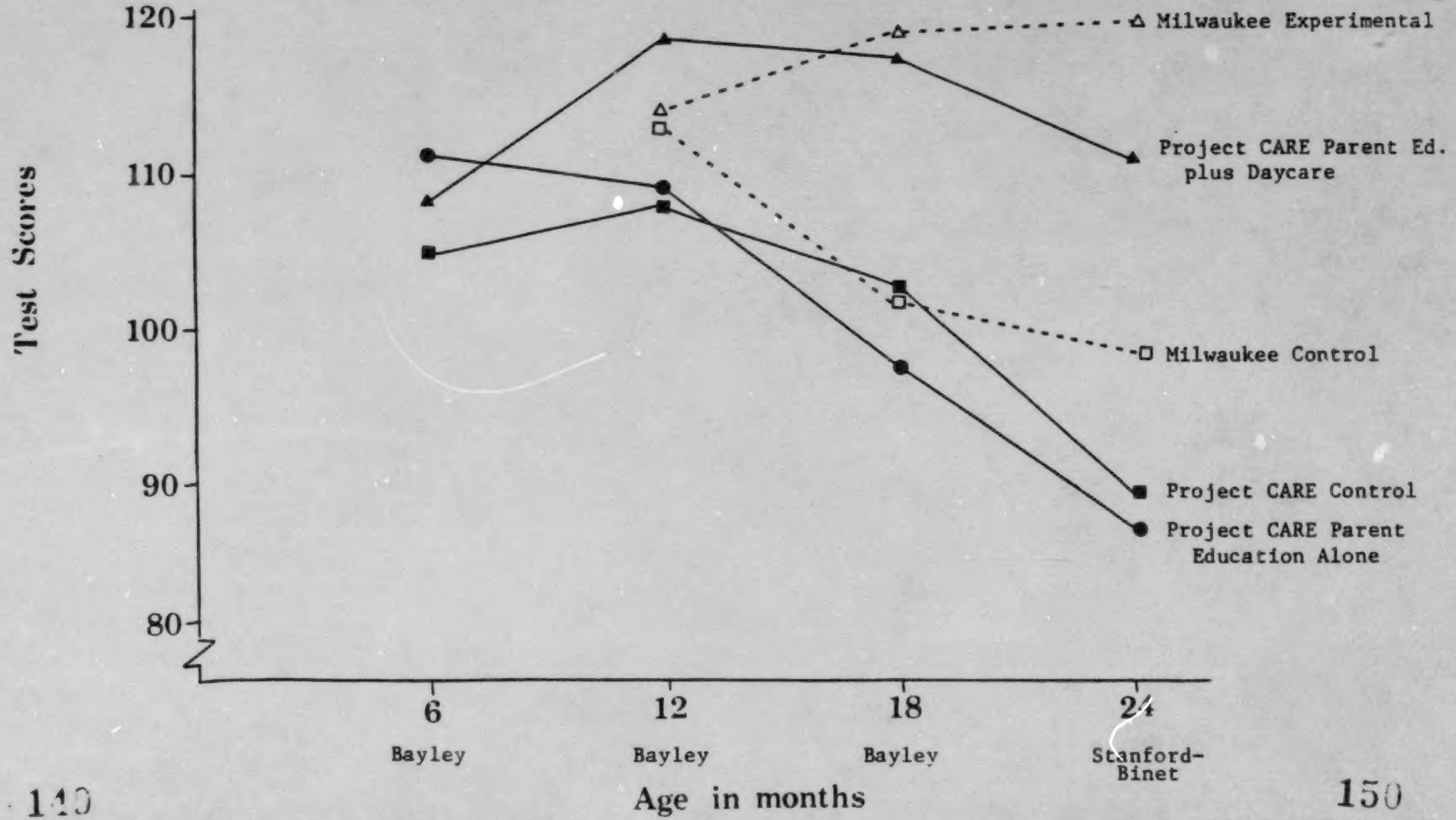
The performance of the most intensely treated group, Daycare plus Family Education, is also noteworthy. Its intensity of treatment is comparable to the Milwaukee Project reported by Garber and Heber, (1977). Figure 11-3 contains a plot of available data from both projects through 24 months of age. At 18 months the Bayley MDI performance for both experimental and control groups from each project are nearly identical. At 24 months, when the Stanford-Binet was used, the scores of the comparable Project CARE groups drop about 10 points below the Milwaukee Project, a difference probably accounted for by Project CARE's use of the 1972 Stanford-Binet norms. Thus, Project CARE's early intellectual findings seem to be replicating those from the Milwaukee Project. However, additional longitudinal intervention and follow-up is required to confirm these trends.

Data collected on child temperament characteristics indicate no significant differences between groups. The Toddler Temperament Scale (Fullard, McDevitt, & Carey, 1978) was completed by the mothers when their children were one year old. The mean temperament profile at 12 months for all three high-risk groups falls within the normal range on all nine temperament factors, although high-risk mothers may tend to view their children as somewhat more arythmic and difficult than do middle-class mothers. This lack of differences between groups is not surprising, given that the intervention program did not attempt to modify personality characteristics.

Family variables. Most intervention projects in the past have focused too narrowly on the child. Outcome measures in Project CARE included not only child development measures, but longitudinal measures of family income, stability of residence, mother employment,

Figure 11-3

Bayley MDI and Stanford Binet IQ Scores
for High-Risk Children in Project CARE
and the Milwaukee Project



quality of home environment, maternal teaching style, maternal problem solving, and mother-child interaction. These measures have been collected according to a schedule previously shown in Table 11-2.

One of the outcomes of particular interest is a measure of the degree of stimulation offered in the child's home environment. Since day care programs have not affected the home (Ramey & Haskins, 1981), it is important to ask whether or not such an effect might be produced by a parent education program (via home visitation), either singly or coupled with day care. The home stimulation data gathered at 6, 12 and 18 months of child age show some slight indication that the home environment may have been influenced in the two experimental groups. For example, the total HOME scores increase from 30.0 to 31.9 to 32.0 for the Parent Education Plus Day Care group. For the Parent Education Alone group it increased from 27.5 to 28.6 to 29.6. The untreated control shows no such trend but begins with a score of 30.2 and ends with a 30.4 score.

A question of particular interest is whether a parent education home visit program, either alone or in addition to daycare, can affect a parent's behavior with her child. From the 12-month videotaped free play situation (described in Appendix A) several of the most important behaviors, such as mutual play with toys, mutual play with books, or mother demonstrates activity, showed a direction of effects with the Daycare plus Family Education group more optimal than Family Education Alone which was more optimal than the Control group (Bryant, Ramey, & Burchinal, 1982). Figure 11-4 presents results from the free play situation for two composite measures that describe this interaction.

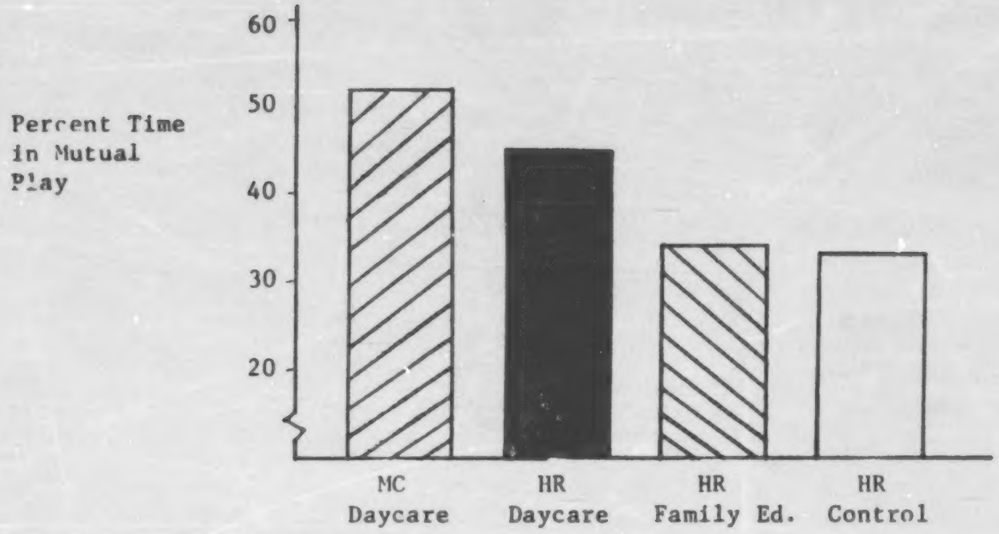
In the first histogram, mutual play includes time spent by the mother and child pair playing with toys or reading together. The four groups are the middle class Daycare plus Family Education comparison group, the high-risk Daycare plus Family Education group, the high-risk Family Education Alone group, and the high-risk Control group. A one-way analysis of variance shows that the groups differ significantly, and t-test comparisons show that the high-risk Daycare plus Family Education group does not differ significantly from the middle class comparison group, but that the other two high risk groups do differ significantly from the middle class comparison group.

The second histogram presents results from another composite variable: percent of time mother involved with child. This includes time spent playing with child, demonstrating to child, and watching the child (ready and available for interaction although not currently engaged actively with child). Here again, the t-test comparisons indicate that the middle class and high-risk Daycare plus

Figure 11-4

Mother-Child Interaction Behaviors

at 12 Months

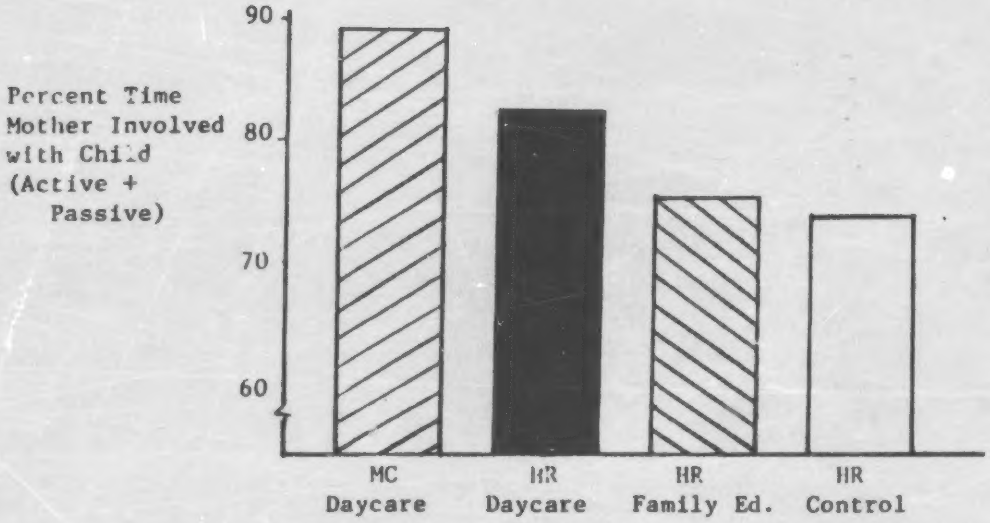


t-test Results

MC Daycare-HR Daycare
NS

MC Daycare-HR Family E
p < .05

MC Daycare-HR Control
p < .01



MC Daycare-HR Daycare
NS

MC Daycare-HR Family Ed.
p < .05

MC Daycare-HR Control
p < .05

(MC = Middle class; HR = High risk)

Family Education groups do not differ significantly, but that the other two high-risk groups do differ from the middle class comparison group.

These results seem to indicate that a parent-focused home visit program can alter a parent's interaction with her 1-year-old child, but is much more likely to do so when other supports are provided, such as daycare for the child.

Discussion and Recommendations

Project CARE has successfully implemented and conducted an early intervention program for children at-risk for developmental retardation. We established a procedure for intervention as well as the development of materials for use by high-risk families. Project CARE has documented what resources and procedures are actually necessary to run a home visit program. As a result, we are able to provide nuts-and-bolts type information for educators about the actual process of family education via a home visit program.

Assessment materials developed in Project CARE, such as the Knowledge of Infant Development Inventory and the Parent Problem Solving Instrument, should be useful to educators interested in parent attitudes and skills and how parent characteristics relate to child functioning. These measures can be used for high-risk and non-high-risk parents.

The current trends from this research hold promise for both educational and scientific impact on the scholarly community. Results have direct relevance to public policies for high-risk infants and their families. The initial results suggest that variations in intensity of preventive treatments are positively related to the developmental status of young children. The 2-year Binet scores of Project CARE children are 10 points higher than the 2-year Binet scores of the daycare only treatment group in the Carolina Abecedarian Project, the forerunner of Project CARE at the Frank Porter Graham Center. These findings have the potential of reconciling some of the apparently anomalous findings from the early intervention literature. Specifically, the current debate over child versus parental approaches to prevention might be partially resolved by our results showing that a combination of these approaches is more powerful and therapeutically helpful than either approach alone. Further, this project, because of its systematic variation of treatments within the design of a true experiment, and because of its emphasis on evaluation of parenting changes, continued to study the psychological mechanisms through which positive results are obtained.

It is obvious to us that to have a more detailed understanding of the consequences of these prevention efforts, these children and their families should be studied until they enter public school. The broad range of program evaluation data available to us, coupled with a randomized research design, allows us potentially to make unique contributions both to the practice of early educational intervention programs and to the theoretical literatures which provide the rationale for service delivery efforts.

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(CIREEH products, cited in this section, are referenced in the Products List in Chapter 13.)

CHAPTER 12

Dissemination

Joseph Sanders

Introduction

CIREEH dissemination was carried out by both the investigators and the FPG Communications Office. Investigators were responsible for reporting results to their research colleagues and specific target audiences of service professionals. The Communications Office was responsible for helping investigators reach broader audiences. The Office is directed by Joseph Sanders and staffed by a science writer and half-time secretary.

Dissemination Model

The organization of dissemination activities between the CIREEH investigators and the Communications Office can be conceptualized as a ladder. The detailed information of the scholarly journal article, conference presentation, or assessment instrument is the first rung of the ladder. This information must be synthesized and combined with information from other articles and interviews for inclusion in technical reports, monographs, and workshops. Further modification and simplification of the message makes it suitable for publication in magazines and the Developments newsletter (published by the FPG Center for a national audience). A final simplification translates the material into a news release, brochure, or slide/tape package.

By following this progression CIREEH achieved dissemination with an economy of effort: each step involved only a further translation of material that had been developed at the previous rung of the ladder.

Summary of Scholarly Dissemination

Since 1977, 105 journal articles, chapters, monographs and similar CIREEH scholarly publications have been published or are in press. Several curricula and instruments have been developed. Approximately 193 scholarly presentations and workshops have been given. In addition, most CIREEH investigators provided consultation to service programs and organizations. The specific dissemination activities of CIREEH projects are reported in this section under the heading, "Project Activities."

General Dissemination

The Communications Office provided technical support to CIREEH investigators by advising on printing techniques and costs, arranging interviews by journalists, maintaining a national mailing list, arranging for photography, and consulting on audiovisual techniques and services. The office helped CIREEH investigators place material in national circulation publications such as Parents magazine (Nancy Johnson), Children Today (Craig Ramey, Jean Gowen, and Earl Schaefer), and Human Services News (Earl Schaefer).

Approximately 150 HCEEP projects received regular communications from CIREEH as part of the FPG Center's national mailings; these mailings brought information about CIREEH to more than 2,000 readers nationally. Information released regularly included the Developments newsletter, CIREEH abstracts of scholarly articles, the CIREEH Status Report, and the annual Progress Report of the FPG Center (which contained a section devoted to CIREEH). Over 22,000 copies of publications containing information about CIREEH were distributed from the Communications Office. The audiences that received mailings of CIREEH products are shown in Table 12-1. In addition, the Communications Office staffed display booths at three national conferences for the purpose of distributing materials from all four early childhood research institutes. The conferences were: 1979 CEC Conference, 1980 HCEEP Conference, and the 1982 CEC Conference.

The Families at Risk project was added to CIREEH when Dr. Bristol joined the Center in 1980. The activities below, then, cover only the time period from July 1, 1980 to the present.

Approximately 70 requests for information regarding the Families at Risk research have been received. Persons requesting these materials include regular and special education teachers, LEA and SEA administrators, researchers, parents, consumer organizations, and physicians. The average request was for approximately two products or documents; 140 products were distributed in all.

In addition to scholarly papers or chapters described elsewhere in this report, dissemination activities included:

1. The distribution by the Council of Exceptional Children of 1,000 free copies of Autistic Children in Public School, (Schopler & Bristol, 1981) to public school teachers, administrators, and University training personnel.

2. Reports of research findings in TEACCHERS REPORT, a newsletter sent to all teachers and administrators of programs for autistic children in N.C.

3. Summaries of Families at Risk research were included in the TEACCH annual report which is sent to 1,000 parents, practitioners, state legislators, and members of the U.S. Senate and House.

Instruments developed by the Family Relations Project are being used in research and evaluation at Yale University, Rutgers, the University of Arkansas at Little Rock, and in service programs in Michigan, New York, Germany, Australia, Israel, and New Zealand. In all, Dr. Schaefer's staff have mailed 185 copies of instruments and papers; they have distributed many more at conferences.

The Parent Involvement Studies has disseminated four types of products: (1) literature reviews, (2) parent satisfaction instruments, (3) parent involvement scales, and (4) project reports and papers. These have been disseminated to all HCEEP projects since 1978 and total well over 200 copies per item. These materials have also been disseminated at over 15 conferences and workshops involving more than 1,500 persons in total. In addition, requests for copies of the various materials are received monthly and have averaged about five requests per month since 1978 or approximately 240 specific requests. Currently, 24 early childhood programs in six eastern states are using the Parent Involvement Scale to conduct pre-and post-evaluations of their parent participation programs. Requests from users of the materials for additional forms and reports indicate that the scales and instruments are helpful in analyzing parent participation.

The Mainstreaming Project has answered requests for 60 copies of published articles and 345 conference presentations. The project developed its own mailing list of parents and professionals who assisted with the study.

The number of inquiries about the Carolina Record of Individual Behavior (CRIB) and various aspects of the Child Assessment Project's research has increased over the past few years as knowledge of the CRIB has become more widespread. In 1981 and 1982, project staff were contacted by more than 25 individuals for information about the uses of the CRIB, independent of requests for journal articles and conference presentations. Those interested have included direct service providers, researchers, physicians, and university faculty. They have represented many states in America as well as the countries of Mexico, Norway, Australia, and Puerto Rico.

Each of the 27 programs that worked with this research effort received reports of research results as they became available.

There have been 25-30 requests for reprints of the chapter on child assessment in *New Directions*. The other journal articles have had a total number of requests in excess of 300. Copies of conference presentations have been requested by at least 100 persons.

Well in excess of 1,000 inquiries have been processed regarding the *Carolina Curriculum for Handicapped Infants* produces by the Child Development Project. Over the past two years, an average of five to six written requests have been answered each week, and a range of one to five telephone correspondences have been completed each week regarding the products being developed. Requests for information and/or copies of the curriculum materials have been received from all 50 states, the District of Columbia, the Virgin Islands, Puerto Rico, and three foreign countries.

A total of 550 copies of the *Carolina Curriculum for Handicapped Infants* (Birth to 12 months) have been distributed. Fifty were used for field test purposes. The others were distributed at cost to individuals and programs requesting them to participate in workshops. They have been distributed in more than 40 states, several United States territories, and three foreign countries.

Distribution of the complete curricular package (birth to 2 years) has been limited to 50 copies. It has been distributed only for the purpose of field testing.

An overwhelming number of requests for the curriculum materials developed in this project have come from programs providing direct service to handicapped infants and toddlers. In addition, programs serving older, severely and profoundly handicapped children who are functioning within the developmental range of birth to 24 months have made many requests for the materials.

Requests for the materials have also come directly from the parents of handicapped children who are interested in using it as a curricular base for intervention which they can take with them as they move from one city to another seeking services for their children, and from university programs training teachers to work with severely/multiply handicapped children.

In response to the need for these materials, University Park Press has negotiated a contract to publish them and make them available commercially in the near future. One state (Louisiana) obtained permission from the authors to make copies of the curricular materials and distribute them to all of the early intervention programs in that state. This was done with the field test version of the birth-to-12-months curriculum.

Bibliographies from Project CARE have been mailed to the 1,300 people on Frank Porter Graham's mailing list. In addition, we have mailed, on request, over 2,500 copies of articles or papers about Project CARE. The Learningames curriculum was purchased and distributed by the State of North Carolina to 500 preschool early education programs that were all or partially state-funded. Since Learningames was published commercially, about 200 requests for information about the curriculum have been received. Innumerable copies of it were mailed out over the previous years when the curriculum was in earlier forms.

Three projects that we know of are using the design and/or curriculum of Project CARE as a model for their programs. The Robert Wood Johnson Foundation and ACYF are currently investigating the possibility of establishing a network of sites dealing with prevention, based on the knowledge they have gained from Project CARE. Joy Osofsky at the Menninger Foundation is beginning a study using Project CARE as a model. An intervention program for children with cerebral palsy, currently being conducted at the J. F. Kennedy Center at Johns Hopkins, is using Learningames as their curriculum, and several other projects around the country use Learningames in combination with other curricula.

A group of three researchers from the University of Washington's National Center for the Assessment of Delinquent Behavior and its Prevention recently spent two days with Project CARE's staff. They sought information about our research procedure, delivery system, and organizational set-up. Their purpose was to get information and materials from our project to use in their early intervention program, a longitudinal study of delinquency being carried out in six school systems throughout the country.

Table 12-1

Mailing List for CIREEH Publications (FPG Mailing List)

Groups	Code	# of Names
I. **Governmental**		
A. Federal	001	50
B. State		
1. N.C.	002	50
2. Non-N.C.	003	20
C. Local		
1. N.C.	004	6
2. Non-N.C.	005	3
II. **Political Leaders**		
A. National	010	110
B. State		
1. N.C. legislators	020	25
2. N.C. elected-executive branch	025	2
3. Non-N.C.	030	0
III. **Schools**		
A. Headstart, preschools, and daycare	055	43
B. Elementary, junior, and high schools	060	37
IV. **Colleges and Universities**		
A. N.C.	070	111
B. Non-N.C.	080	121
V. **Researchers, Research Centers, Center Directors, Residential**		
A. University affiliated (U.A.F.)	090	40
B. Mental retardation research centers	100	44
C. Research centers, hospitals, rehabilitation and service agencies	110	61
D. Research and demonstration centers	120	112
E. CIREEH	125	145

Table 12-1 (Cont.)

Groups	Code	# of Names
IV. Education, Mental Retardation, Handicapped, Adovacy-Related Agencies, Foundations, and Individuals		
A. N.C.	130	37
B. Non-N.C.	140	78
VII. Media and Information		
A. Press, radio, and T.V.		
1. N.C.	150	40
2. Non-N.C.	160	104
B. Information officers, information clearinghouses, house organs		
1. N.C.	170	25
2. Non-N.C.	180	46
3. E.R.I.C. and libraries	190	38
VIII. Technical Assistance	200	10
IX. Child and Family Policy	210	23
TOTAL		1381

NOTE: Approximately 700 additional copies of each publication are mailed in response to individual requests or are distriuted at meetings and conferences.

CHAPTER 13

CIREEH PRODUCTS AND PRESENTATIONS

Curricula, Manuals, and Instruments

DeVellis, R., Revicki, D., & Bristol, M. M. *Child Improvement Locus of Control Scales* (CILC). Unpublished assessment instrument, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 1981.

Gallagher, J. J., Cross, A., & Scharfman, W. *Parent Role Scale* (Two-Parent Version). Unpublished assessment instrument, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 1980.

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Lewis, I., & Sparling, J. *Careteacher Skills: A Teacher Training Curriculum*. Unpublished curriculum, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 1982.

MacPhee, D. *Knowledge of Infant Development Inventory*. Unpublished assessment instrument, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 1980.

Schaefer, E. S., & Edgerton, M. *Parent as Educator Inventory* (Short Form). Unpublished instrument, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 1979.

Schaefer, E. S., & Edgerton, M. *Classroom Behavior Inventory* (Preschool Form). Unpublished instrument, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 1978.

Schaefer, E. S., & Edgerton, M. Social Assets Inventory. Unpublished instrument, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 1979.

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Schaefer, E. S., & Edgerton, M. *Marital Autonomy and Relatedness Inventory*. Unpublished instrument, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 1979.

Schaefer, E. S., & Edgerton, M. *Child-rearing and Education Research Instrument*. Unpublished instrument, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 1980.

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Wasik, B. H. (Ed.), *Home visiting in Project CARE*. Unpublished manual, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 1982.

Wasik, B. H., Bryant, D. M., & Fishbein, J. *Parent Problem Solving Instrument*. Unpublished assessment instrument, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 1982.

Books, Chapters, and Monographs

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Jens, K. G., & Johnson, N. M. Developing curricula for severely/multiply handicapped infants and toddlers. Experimental Education Unit, University of Washington, Seattle, November 1980.

Jens, K. G., & Johnson, N. M. Developing curricula for severely/multiply handicapped preschool children. Handicapped Children's Early Education Project Directors' Conference, Washington, DC, December 1980.

Jens, K. G., & Johnson, N. Developing assessment and intervention systems for use with severely handicapped infants. Division for Disorders of Development and Learning, University of North Carolina, Chapel Hill, March 1980.

Jens, K. G., & Johnson, N. Developing empirically based curricula for severely handicapped infants and toddlers. First Step-Preschool Handicapped Institute, Columbia, SC, March 1980.

Jens, K. G., & O'Donnell, K. Assessing affective development of handicapped youngsters: Do usable landmarks exist? BEH Invitational Conference--Handicapped and At-Risk Infants: Research and application, Monterey, CA, April/May 1980.

Johnson, N. Assessment strategies for handicapped infants. Technical Assistance Development System, Chapel Hill, NC, March 1980.

Johnson, N. New assessment paradigms: Do the ends justify the means? BEH Invitational Conference--Handicapped and At-Risk Infants: Research and Application, Monterey, CA, April/May 1980.

Johnson, N. Play in the curriculum of handicapped infants.

Nebraska Symposium on Play, Omaha, May 1980.

Johnson, N. *Curriculum for Handicapped Infants*. New England Conference on Biologically Impaired Infants, Providence, RI, June 1980.

Johnson, N., & Jens, K. *Curriculum development and non-traditional assessment strategies for use with severely/multiply handicapped infants*, New Orleans, LA, May 1980.

Johnson, N., Jens, K., et. al. *Assessment and programming for severely/multiply handicapped infants and pre-schoolers*. Division for Disorders of Development and Learning, University of North Carolina at Chapel Hill, May 1980.

Leonard, J. *Legal and ethical issues in research with handicapped children and their families*. American Association on Mental Deficiency, San Francisco, CA, May 1980.

Lewis, I. *Infant curriculum*. Durham Day Care Council, Durham, NC, April 1980.

Ramey, C. *What research tells us about the young handicapped child and his family*. Georgia Conference on Handicapped Children, Athens, February 1980.

Ramey, C. T., & Farran, D. C. *Patterns of dyadic involvement: Infancy to public school*. International Conference on Infant Studies, New Haven, CN, April 1980.

Ramey, C. T., & Baker-Ward, L. *Psychosocial retardation and the early experience paradigm*. Conference on High-Risk Infants sponsored by Bureau for the Education of the Handicapped. Monterey, CA, April 1980.

Ramey, C. T. *Psychological and biomedical consequences of preschool intervention*. Colloquium delivered at Johns Hopkins University School of Medicine, Baltimore, MD, April 1980.

Ramey, C. T., & Haskins, R. *Causes and treatment of school failure: Insights from the Carolina Abecedarian Project*. American Educational Research Association, Boston, MA, April 1980.

Ramey, C. T. *Modifying the development of infants: Preventing developmental problems*. Vermont Conference on Primary Prevention sponsored by the University of Vermont, Burlington, VT, June 1980.

Ramey, C. T., Finkelstein, N. W., & Campbell, F. A. *Structure and correlates of intellect in socially high-risk children.* Conference on Learning and Cognition in Mental Retardation sponsored by NICHHD. Nashville, TN, September 1980.

Ramey, C. T. *The efficacy of primary prevention of developmental retardation*. Conference on Early Childhood Development, sponsored by U.S. Office of Special Education, Washington, DC, December 1980.

Schaefer, E. *Parent-professional interaction*. Parent Education and Public Policy Conference, Roxboro, NC, March 1980.

Schaefer, E. *Professional roles in family support systems*. University of Missouri, Columbia, April 1980.

Schaefer, E. *Methods for studying child and family adaptation.* Workshop on Social-Emotional/Affective Assessments, Washington, DC, June 1980.

Schaefer, E. S., & Edgerton, M. *Evidence of parent and teacher validity in screening for handicaps*. American Public Health Association, Detroit, MI, October 1980. (ERIC No. 202 300 *Resources in Education*, September 24, 1981)

Simeonsson, R. J. *Characteristics of behavior and temperament in young handicapped children: Implications for documentation of progress*. Handicapped Children's Early Education Project Directors' Conference, Washington, DC, December 1980.

Simeonsson, R. & Huntington, G. *Developmental and behavioral correlates of rhythmic habit patterns in handicapped infants*. Gatlinburg Conference on Mental Retardation, Gatlinburg, TN, March 1980.

Simeonsson, R. & Huntington, G. *Correlates of developmental progress in handicapped infants*. International Conference on Infant Studies, New Haven, CT, April 1980.

Simeonsson, R., Huntington, G. & Parse, S. *Expanding the assessment of handicapped infants: A research report*. Council for Exceptional Children, Philadelphia, PA, April 1980.

Simeonsson, R., Jens, K., Johnson, N., & Huntington, G. *Assessing development in moderately/severely/multiply handicapped preschool children*. Handicapped Children's Early Education Project Directors' Conference, Washington, DC, December 1980.

Simeonsson, R. J., Johnson, N. M., Jens, K. G., & Huntington, G. S. *Instruments and strategies to assess the young handicapped child*. Handicapped Children's Early Education Project Directors' Conference, Washington, DC, December 1980.

Swanson, J., Johnson, N. M., & Jens, K. *Assessment of preterm and posterm infants*. Health Care/Education Relationship Topical Workshop, New Orleans, LA, March 1980.

Turnbull, A. *Mainstreaming: An empirical and conceptual review*. American Educational Research Association, Boston, MA, April 1980.

Turnbull, A. *Mainstreaming and parents*. American Association on Mental Deficiency, San Francisco, CA, May 1980.

Turnbull, A. *Impact of mainstreaming on parents*. Council for Exceptional Children, Philadelphia, PA, April 1980.

Wasik, B. H. *Theories of problem solving and applications for the training of psychologists and parents*. Invited colloquium, Department of Psychology, UNC-Greensboro, October 1980.

Wiegerink, R. *Parent involvement in early childhood programs for the handicapped*. Health Issues and Early Intervention Program for Handicapped Children Birth to Three, Washington, DC, May 1980.

Wiegerink, R., & Hocutt, A. M. *Four perspectives on parent involvement in preschool programs for handicapped children*. Bush Institute Conference on Parent Education and Public Policy, Quail Roost Conference Center, Rougemont, NC, March 1980.

Winton, P. *Parent perspectives on involvement in preschool educational programs*. American Educational Research Association, Boston, MA, April 1980.

1981

Blacher-Dixon, J. *Consistency and correspondence of maternal and teachers' assessment of behavior*. In R. Simeonsson (Chair), Infant behavior and temperament: Clinical application of the CRIB and temperament scales. Symposium presented at the Gatlinburg Conference on Research in Mental Retardation/ Developmental Disabilities, Gatlinburg, TN, March 1981.

Blacher-Dixon, J. *Consistency and correspondence of maternal and teachers' assessments of behavior*. In R. J. Simeonsson (Chair), Infant behavior and temperament: Clinical applications of the CRIB and temperament scales. Symposium presented at the meeting of the Society for Research in Child Development, Boston, MA, April 1981.

Blacher-Dixon, J., & Simeonsson, R. *Consistency and correspondence of mothers' and teachers' assessment of young handicapped children*. Society for Research in Child Development, Boston, MA, April 1981.

Bristol, M. M. *Burn out: Dealing with stress and the special needs child*. Invited Keynote Address, New England Regional Program Conference on Parenting and the Special Child, Keene, NH, April 1981.

Bristol, M. M. *Families of handicapped children*. An invited workshop, Keene State College, Keene, NH, April, 1981.

Bristol, M. M. *Sources of help for parents of autistic children*. International Meeting of the Society for Autistic Children, Boston, MA, July 1981.

Bristol, M. M. *Direct and indirect effects of handicapped children on families*. OSE/HCEEP Conference, Washington, DC, December 1981.

Bristol, M. M. *Predicting and ameliorating stress in families of autistic children*. TEACCH Inservice Training Conference for Teachers of Autistic Children. Sanford, NC, March 1981.

Gallagher, J. J. *Speakers and listeners--A communications problem*. OSE/HCEEP Conference, Washington, DC, December 1981.

Gowen, J. *Assessing the development of the symbolic function through play*. OSE/HCEEP Conference, Washington, DC, December 1981.

Huntington, G. S. Correlates of development: Progress in impaired infants and children. In R. Simeonsson (Chair), *Infant behavior and temperament: Clinical application of the CRIB and temperament scales.* Symposium presented at the Gatlinburg Conference on Research in Mental Retardation/ Developmental Disabilities, Gatlinburg, TN, March 1981.

Huntington, G. S., & Bryant, D. M. Correlates of development: Progress in impaired infants and children. In R. Simeonsson (Chair), *Infant behavior and temperament: Clinical application of the CRIB and temperament scales.* Symposium presented at the meeting of the Society for Research in Child Development, Boston, MA, April 1981.

Jens, K. *Guidelines for the evaluation of curricula for the severely handicapped.* Southeastern Regional Coalition for the Severely Handicapped, Rougemont, NC, May 1981.

Jens, K. *Alternative strategies for assessing development in young handicapped children.* Symposium on the Assessment and Education of Handicapped Infants, Baltimore, MD, August 1981.

Jens, K. *Choosing curricula for use with moderately and severely handicapped young children.* Association for the Severely Handicapped, New York, NY, October 1981.

Jens, K. *Developing curricula for severely handicapped young children.* Illinois Institute for Developmental Disabilities, Chicago, IL, October 1981.

Jens, K. *Early intervention for handicapped infants: A high yield investment.* Charles E. Downing Invited Memorial Lecture, Milwaukee, WI, October 1981.

Jens, K., Johnson, N., O'Donnell, K., & Gallagher, R. *Developing educational programs for preschool severely handicapped children: Identification, assessment and curriculum development.* Council for Exceptional Children, New York, NY, April 1981.

Johnson, N. *Assessment problems and strategies for severely handicapped infants.* New England Conference on Early Intervention Programs, Boston, MA, April 1981.

Johnson, N. *Enhancing mother-child interaction: The first step in intervention with handicapped infants.* TAP-IN Conference for Early Interventionists, Raleigh, NC, May 1981.

Johnson, N. *Assessment and intervention with the visually impaired infant.* Inservice Training for Independent Living Counsellors, Fayetteville, NC, May 1981.

Johnson, N. *Assessment in infant education: Paradigms and problems.* Symposium on the Assessment and Education of Handicapped Infants, Baltimore, MD, August 1981.

Johnson, N. *Infant assessment: Current problems and directions for research.* North Carolina Psychological Association, Asheville, NC, September 1981.

Johnson, N. M., Attermeier, S. M., & Jens, K. G. *Assessment of atypical infants: Problems and strategies.* University Affiliated Program for Handicapped Preschoolers, Winthrop College, Rock Hill, SC, January 1981.

Johnson, N., & Jens, K. *Curriculum development and alternative assessment strategies for handicapped infants.* The Graduate Institute, Southeastern Regional Coalition of Universities, Preparing Personnel to Work with the Severely Handicapped, Atlanta, GA, March 1981.

Johnson, N., & Jens, K. *Developing effective teams to work with handicapped infants and their parents.* New England Conference on Early Intervention Programs, Boston, MA, April 1981.

MacPhee, D., & Ramey, C. T. *Infant temperament as a catalyst and consequence of development in two caregiving environments.* Gatlinburg Conference on Research in Mental Retardation/Developmental Disabilities, Gatlinburg, TN, March 1981.

McHale, S. M. Social interaction of autistic children. In R. J. Simeonsson (Chair), *Infant behavior and temperament: Clinical application of the CRIB and temperament scales.* Symposium presented at the meeting of the Society for Research in Child Development, Boston, MA, April 1981.

McHale, S., & Simeonsson, R. J. *Relationships between children and their handicapped and nonhandicapped siblings.* Gatlinburg Conference on Research in Mental Retardation/ Developmental Disabilities, Gatlinburg, TN, March 1981.

Parse, S. A. Comparison of maternal and professional. In R. J. Simeonsson (Chair), *Infant behavior and temperament: Clinical application of the CRIB and temperament scales.* Symposium presented at the meeting of the Society for Research in Child Development, Boston, MA, April 1981.

Ramey, C. T. *Insights from a home-based parent education program*. Piedmont Infant Mental Health Association. Raleigh, NC, February 1981.

Ramey, C. T. *Preventing developmental retardation: A general systems perspective*. Gatlinburg Conference on Research in Mental Retardation/Developmental Disabilities. Gatlinburg, TN, March 1981.

Ramey, C. *Families of disadvantaged children*. Conference on Early Childhood Development Disabilities: The status of current prevention efforts, Oxford, MS, April 1981.

Ramey, C. *Preventing developmental retardation: A general systems theory model*. Midwestern Psychological Association, Detroit, MI, April 1981.

Ramey, C. *Psycho-social retardation: Early intervention and follow-up*. Symposium on Developmental Disabilities: The status of current prevention efforts, Oxford, MS, April 1981.

Ramey, C. *A systems theory perspective on disadvantaged families*. Department of Psychology, Case Western Reserve University, Cleveland, OH, April 1981.

Ramey, C. *Treatment programs for the exceptional infant*. School of Education, Boston, MA, May 1981.

Ramey, C. *Evidence for primary prevention of developmental retardation during infancy*. OSE/HCEEP Conference, Washington, DC, December 1981.

Ramey, C. *Identification procedures for infants at-risk for developmental retardation*. OSE/HCEEP Conference, Washington, DC, December 1981.

Ramey, C., & Brownlee, J. *A methodology for identifying infant at-risk for developmental retardation*. Society for Research in Child Development, Boston, MA, April 1981.

Schaefer, E. *The family environment, intellectual development, and the quality of life*. International Year of the Disabled Person Symposium, Duke University, Durham, NC, November 1981.

Schaefer, E. *Family structure and function, child adaptation and service needs*. OSE/HCEEP Conference, Washington, DC, December 1981.

Schaefer, E. S., & Edgerton, M. *Parental modernity in childrearing and educational attitudes and beliefs*. Society for Research in Child Development, Boston, MA, April 1981. (ERIC No. ED 202 605); *Resources in Education*, September 24, 1981)

Short, R. Rhythmic habit patterns and behavioral development. In R. Simeonsson (Chair), *Infant behavior and development*. Symposium presented at the Gatlinburg Conference on Research in Mental Retardation/Developmental Disabilities, Gatlinburg, TN, March 1981.

Simeonsson, R. J. (Chair). *Symposium: Infant Behavioral Temperament--Clinical applications of the CRIB and temperament scales*. Society for Research in Child Development, Boston, MA, April 1981.

Simeonsson, R. (Discussant). *Families of handicapped children*. Meeting of the Society for Research on Child Development, Boston, MA, April 1981.

Simeonsson, R. *Assessment of young handicapped children in preschool context*. Kentucky's Individual Kindergartens Training Institute Meeting, Louisville, KY, July 1981.

Simeonsson, R. & Cooper, D. *Early intervention for developmentally disabled children: A review and analysis of effectiveness*. Conference on Current Concepts in the Care of the High Risk Infant, Worcester, MA, June 1981.

Simeonsson, R., & Cooper, D. *A critical analysis of research on effectiveness of early intervention*. OSE/HCEEP Conference, Washington, DC, December 1981.

Simeonsson, R., Huntington, G., & Short, R. *Temperament and behavior in young children with sensory or motor impairments*. International Society for the Study of Behavioral Development Meeting, Toronto, Canada, August 1981.

Simeonsson, R., Huntington, G., & Short, R. *Temperament characteristics of young handicapped children*. OSE/HCEEP Conference, Washington, DC, December 1981.

Sparling, J. J. *Evaluating the effectiveness of family involve-*

ment in Project CARE. OSE/HCEEP Conference, Washington, DC, December 1981.

Turnbull, A. *Parent involvement in early childhood special education: Paradoxes and contradictions.* Minnesota Round Table in Early Childhood Education VIII, June 1981.

Turnbull, A. *Parents' perspectives on mainstreaming and specialized preschool services.* American Association on Mental Deficiency, Detroit, MI, May 1981.

Wasik, B. *Problem solving training with parents of young children.* Association for the Advancement of Behavior Therapy, Toronto, Canada, November 1981.

Wasik, B. H. *Parenting and problem solving: Is there a relationship?* OSE/HCEEP Conference, Washington, DC, December 1981.

Wasik, B. H. *Problem solving skills and parenting: Is there a relationship?* Handicapped Children's Early Education Project/Office of Special Education Director's Conference, Washington, DC, December 1981.

Wasik, B., Bryant, D., & Fishbein, J. *Assessing problem solving skills of parents.* Association for the Advancement of Behavior Therapy, Toronto, Canada, November 1981.

Wiegerink, R. *Parent involvement in IEP meetings: Revelations of recent research.* George Mason University's College of Professional Studies, Mainstreaming and Normalization for the Handicapped: Goals and Results, Arlington, VA, June 1981.

Wiegerink, R. *Preschool efficacy and parent involvement.* Minnesota Round Table in Early Childhood Education, Minneapolis, MN, June 1981.

Wiegerink, R. *Early education: Review and preview.* Minnesota Conference on Early Education for the Handicapped, Minneapolis, MN, September 1981.

Wiegerink, R. *State of the art and current issues in family intervention strategies.* OSE/HCEEP Conference, Washington, DC, December 1981.

Winton, P. *Parents with handicapped children: Transition to preschool: Needs of the 90's.* Research Conference on Young

Children and Their Families, Anaheim, CA, June 1981.

Winton, P., & Turnbull, A. *Coping patterns over time: Mainstreamed versus specialized preschools.* Society for Research in Child Development, Boston, MA, April 1981.

1982

Braitmeyer, B., & Ramey, C. T. *Biosocial vulnerability and quality of postnatal environment as co-determinants of intellectual development.* Gatlinburg Conference on Research in Mental Retardation/Developmental Disabilities, Gatlinburg, TN, April 1982.

Bristol, M. M. *A stress management workshop for directors of parent training centers.* Invited and sponsored by the Early Childhood Section of the Louisiana State Department of Education, Baton Rouge, LA, February 1982.

Bristol, M. M. *A S.A.N.E. SYSTEM for Coping with Stress in Families of Handicapped Children.* Invited paper presented at the Southern Regional (SUPER) Conference, Baton Rouge, LA, February 1982.

Bristol, M. M. *Parent involvement in preschool programs for handicapped children.* Invited paper presented at the Southern Regional (SUPER) Conference, Baton Rouge, LA, February 1982.

Bristol, M. M. *An invited workshop on coping with stress in families of handicapped children.* Southern Association for Children Under Six Conference, Tulsa, OK, March 1982.

Bristol, M. M. *Research Symposium: Career Education* (Panel Moderator). American Association on Mental Deficiency, Boston, MA, June 1982.

Bristol, M. M. *The use of quantitative interviews in research with parents of handicapped children.* American Association on Mental Deficiency, Boston, MA, June 1982.

Bristol, M. M. Stress and coping in families of handicapped children. In M. M. Bristol (Chair), *Symposium on the Carolina Institute for Research on Early Education of the Handicapped: Research findings and implications for practitioners*, American Association on Mental Deficiency, Boston, MA, June 1982.

Bristol, M. M. Stress and coping in families of handicapped children. In N. Johnson (Chair), *Symposium on the Carolina*

Institute for Research on Early Education of the Handicapped: Research findings and implications for practitioners, Second Annual Interact Conferences, Boston, MA, June 1982.

Bristol, M. M. *Fathers of autistic children* (Panel Moderator). National Society for Autistic Children, Omaha, NE, July 1982.

Bristol, M. M., & Schopler, E. *Coping and stress in families of autistic children*. Gatlinburg Conference on Research in Mental Retardation/Developmental Disabilities, Gatlinburg, TN, April 1982.

Bristol, M. M. *Dealing with the family stress of an autistic child* (Panel Moderator). National TEACCH Conference on the Effects of Autism on the Family. Chapel Hill, NC, May 1982.

Bristol, M. M. *Home environment for developmentally disabled children*. University of Washington NICHHD Conference on Environments for Developmentally Disabled Persons, Seattle, WA, August 1982.

Bryant, D., Ramey, C. T., & Burchinal, M. *Intervention effects on mother-child interaction*. International Conference on Infant Studies, Austin, TX, March 1982.

Hocutt, A. M., McKinney, D., & Wiegerink, R. *The implementation of the HCEEP parent involvement policy*. American Association on Mental Deficiency, Boston, MA, June 1982.

Huntington, G. S. *Temperament characteristics of young handicapped children*. Southeastern Conference on Human Development, Baltimore, MD, April 1982.

Huntington, G. S. *Developmental profiles of handicapped and nonhandicapped infants at 6-12 & 18 months*. American Association on Mental Deficiency, Boston, MA, June 1982.

Huntington, G. S. Child assessment project. In M. M. Bristol (Chair), *Symposium on the Carolina Institute for Research on Early Education of the Handicapped: Research findings and implications for practioners*. American Association on Mental Deficiency, Boston, MA, June 1982.

Huntington, G. S. Child Assessment Project. In N. Johnson (Chair), *Symposium on the Carolina Institute for Research on Early Education of the Handicapped: Research findings and implications for practioners*. Interact Conference, Boston, MA, June 1982.

Huntington, G. S., & Short, R. J. *Carolina Record of Individual Behavior: Characteristics of infants and toddlers with Down syndrome*. International Conference on Infant Studies, Austin, TX, March 1982.

Huntington, G. S., & Simeonsson, R. J. *Temperament profiles of Down syndrome toddlers*. Gatlinburg Conference on Research in Mental Retardation/Developmental Disabilities, Gatlinburg, TN, April 1982.

Jens, K. *Non-traditional assessment strategies for use with preschool handicapped children*. Preschool Special Child-Assessment and Management Conference, Chapel Hill, NC, May 1982.

Jens, K. *Linking assessment and curriculum development strategies in designing instructional programs for severely handicapped students*. Southern Regional Education Conference, Baton Rouge, LA, February 1982.

Johnson, N. *Values clarification in early intervention*. Conference for Early Intervention Workers, Tarrboro, NC, January 1982.

Johnson, N. *Working with difficult parents: Identifying problems and planning strategies*. North Carolina Early Intervention Conference--Central Region, Charlotte, NC, February 1982.

Johnson, N. *Infant assessment: The state of the art*. Council for Exceptional Children, Houston, TX, April 1982.

Johnson, N. *Preschool assessment: The tie to curriculum*. Linking Developmental Assessment to Curriculum (Conference sponsored by the NC State Department of Public Instruction), Raleigh, NC, April 1982.

Johnson, N. Curriculum development. In M. M. Bristol (Chair), *Symposium on the Carolina Institute for Research on Early Education of the Handicapped: Research Findings and Implications for Practitioners*. American Association on Mental Deficiency, Boston, MA, June 1982.

Johnson, N. Curriculum development. In N. Johnson (Chair), *Symposium on the Carolina Institute for Research on Early Education of the Handicapped: Research Findings and Implications for Practitioners*. Interact Conference, Boston, MA, June 1982.

Johnson, N. *Working with difficult parents: Identifying problems and planning strategies.* North Carolina Early Intervention Conference, Western Region, Cullowhee, NC, June 1982.

Johnson, N., & Attermeier, S. *The Carolina Curriculum for Handicapped Infants, Preschool Special Child.* Assessment and Management Conference, Chapel Hill, NC, May 1982.

Johnson, N., & Attermeier, S. *The Carolina Curriculum for Handicapped Infants.* Anniversary Symposium at the Division for Disorders of Development and Learning, Chapel Hill, NC, April 1982.

Lewis, I. *Programming for parent involvement in the earliest years of day care.* Southern Association on Children Under Six Conference, Tulsa, OK, March 1982.

MacPhee, D., Baker-Ward, L., & Ramey, C. T. *The effects of model vs. modal daycare on the development of high-risk children.* Southeastern Conference on Human Development. Baltimore, MD, April 1982.

Ramey, C. T. *Systems theory and human development.* Invited conversation hour discussion. International Conference on Infant Studies, Austin, TX, March 1982.

Ramey, C. T., & Yeates, K. O. *Family clusters of children at risk for developmental retardation.* Gatlinburg Conference on Research in Mental Retardation/Developmental Disabilities. Gatlinburg, TN, April 1982.

Ramey, C. T., Yeates, K. O., & Short, B. *A systems theory perspective on the plasticity of intellect.* The Merrill-Palmer Conference on Development. Detroit, MI, May 1982.

Short, R. J. *Rhythmic habit patterns and behavioral development.* Council for Exceptional Children's 60th Anniversary Convention, Houston, TX, April 1982.

Short, R. J., & Simeonsson, R. J. *Rhythmic habit patterns as a function of handicapping condition.* International Conference on Infant Studies, Austin, TX, March 1982.

Simeonsson, R. J. *Goal attainment scaling to evaluate progress of handicapped children.* Council for Exceptional Children's 60th Anniversary Convention, Houston, TX, April 1982.

Simeonsson, R. J. *Chairperson: Empirical and clinical issues in the assessment of temperament.* Southeastern Conference on Human Development, Baltimore, MD, April 1982.

Simeonsson, R. J. *Discussant: Symposium on families of handicapped children.* Gatlinburg Conference on Research in Mental Retardation/Developmental Disabilities, Gatlinburg, TN, April 1982.

Simeonsson, R. J., Cooper, D., & Farran, D. *Socialization and development: A prospective analysis.* Gatlinburg Conference on Research in Mental Retardation/Developmental Disabilities, Gatlinburg, TN, April 1982.

Simeonsson, R. J., & Huntington, G. S. *Temperament profiles of Down syndrome toddlers.* International Conference on Infant Studies, Austin, TX, March 1982.

Simeonsson, R. J., & Short, R. J. *Carolina Record of Individual Behavior (CRIB): Characteristics of infants and toddlers with Down syndrome.* Gatlinburg Conference on Research in Mental Retardation/Developmental Disabilities, Gatlinburg, TN, April 1982.

Turnbull, A. *Normalization in the neighborhood, church and community.* Keynote address at Technical Assistance Delivery System Mainstreaming Conference, Raleigh, NC, March 1982.

Turnbull, A. *Parent-professional partnership for 1980's.* Missouri Council for Exceptional Children, Lake of the Ozarks, MO, March 1982.

Turnbull, A. *Dissemination of research to policy makers: Issues and future directions.* Council for Exceptional Children, Houston, TX, April 1982.

Turnbull, A. *Point-counterpoint forum: Issues in the education of handicapped children.* Association for Retarded Citizens, Kansas ARC, Topeka, KA, April 1982.

Turnbull, A. *Discussant at symposium on parent-researcher relationship.* American Associaton on Mental Deficiency, Boston, MA, June 1982.

Wiegerink, R. *Services integration and consumer involvement.* Special Education Meets the 80's: Year III Conference, Baton Rouge, LA, February 1982.

Winton, P. *Parents' perspective on preschool services: Mainstreamed and specialized.* Technical Assistance Delivery System Conference on Mainstreaming, Raleigh, NC, March 1982.

Winton, P. *Dissemination of research to parents: Issues, barriers and future directions.* Council for Exceptional Children, Houston, TX, April 1982.

Winton, P. *The use of qualitative methods in conducting research with parents of handicapped children: Pros and cons.* American Association on Mental Deficiency Conference, Boston, MA, June 1982.

Winton, P. *Parents' perspectives on preschool mainstreaming: Research findings and implications.* Interact Conference, Boston, MA, June 1982.

Winton, P. *CIREEH research on parent perspectives on preschool mainstreaming: Implications for practitioners.* American Association on Mental Deficiency, Boston, MA, June 1982.

Additions to CIREEH Products and Presentations:

1. Curricula, Manuals, and Instruments

Bryant, D. M., Wasik, B. H., & Fishbein, J. *Manual for Parent Problem Solving Instrument*. Unpublished manual, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 1982.

2. Articles, Reviews and Proceedings

Wasik, B. H., Bryant, D. M., & Fishbein, J. Assessment of low and middle income parents' problem solving skills. *Proceedings of the Association for Advancement of Behavior Therapy*, 1981, Toronto, Cannada, in press.

CHAPTER 14

Research Training Activities

One of the foremost supplementary benefits of an organization such as CIREEH is that it provides opportunities for new scholars in the field to become interested and involved in the research process. A number of research training activities were provided by CIREEH for students and post-doctoral fellows at the University of North Carolina and, to some extent, for students from other places. A major activity was the involvement of the students in the actual research enterprise. Concomitant with this experience were opportunities for some students to write master's theses and dissertations on topics being addressed by CIREEH research. The other major training activity was the opportunity for students both those participating in CIREEH research and other students at the university to attend seminars and colloquia presented by CIREEH and other components of the Frank Porter Graham Child Development Center.

By participating in the actual research process, students were able to work directly with researchers who were seeking new knowledge on important topics. Since 1977, CIREEH has provided research training to 49 students: 7 post-doctoral, 41 graduate, and 1 undergraduate (see Table 14-1). Twelve dissertations have been completed out of this work; two dissertations and one thesis are in process (see Table 14-2 for a list of these products).

By working with CIREEH projects as research assistants, these students and post-doctoral fellows gained experience in the many steps that move a research project from initial planning through data collection and analysis to reporting of results. By participating in planning new studies within the projects, students grappled with the problems of research design, sample selection and procurement, instrument evaluation and selection, and data analysis. By assisting with reviews of the literature, students became informed about the work of other investigators regarding the issues under study.

Students were involved in the data collection process and had an opportunity to gain experience in such aspects of this process as obtaining informed consent, scheduling subjects, administering tests, interviewing subjects, coding observations, and operating various types of laboratory equipment. Their training placed

Table 14-1

CIREEH Research Trainees

Name	Dates Affiliated	Current Position	Current Location
Post-Doctoral Fellows and Investigators:			
*Judy Adams Ph.D.	9/76-6/77	Assistant Professor	Public Health Nursing UNC, Chapel Hill, NC
*John Brownlee, Ph.D.	9/79-6/81	Assistant Professor	Dept. of Consumer & Family Relations University of Utah Salt Lake City, UT
Roger Cox, Ph.D.	2/81-5/81	Director	Psychology, University Affiliated Center for D. D. Children University of Texas Dallas, TX
*Barbara Goldman, Ph.D.	11/80-6/82	Post-doctoral Fellow	CIREEH, FPG Center UNC, Chapel Hill, NC
*Susan McHale, Ph.D.	8/79-7/80	Assistant Professor	Penn State University State College, PA
Robert Orr, Ph.D.	11/80-6/81	Assistant Professor	Dept. of Psychology University of Windsor Windsor, Ontario Cannada, NPB3P4
Jocelyn Weddell-Monnig, Ph.D.	6/81-12/81	Post-doctoral Fellow	Division for Disorders of Development and Learning UNC, Chapel Hill, NC

*Students who also participated in the Frank Porter Graham Child Development Center's Research Training Program

Table 14-1

CIREEH Research Trainees

Name	Dates Affiliated	Current Position	Current Location
Post-Doctoral Fellows and Investigators:			
*Judy Adams Ph.D.	9/76-6/77	Assistant Professor	Public Health Nursing UNC, Chapel Hill, NC
*John Brownlee, Ph.D.	9/79-6/81	Assistant Professor	Dept. of Consumer & Family Relations University of Utah Salt Lake City, UT
Roger Cox, Ph.D.	2/81-5/81	Director	Psychology, University Affiliated Center for D. D. Children University of Texas Dallas, TX
*Barbara Goldman, Ph.D.	11/80-6/82	Post-doctoral Fellow	CIREEH, FPG Center UNC, Chapel Hill, NC
*Susan McHale, Ph.D.	8/79-7/80	Assistant Professor	Penn State University State College, PA
Robert Orr, Ph.D.	11/80-6/81	Assistant Professor	Dept. of Psychology University of Windsor Windsor, Ontario Cannada, NPB3P4
Jocelyn Weddell-Monnig, Ph.D.	6/81-12/81	Post-doctoral Fellow	Division for Disorders of Development and Learning UNC, Chapel Hill, NC

*Students who also participated in the Frank Porter Graham Child Development Center's Research Training Program

Table 14-1 continued

CIREEH Research Trainees

Name	Dates Affiliated	Current Position	Current Location
Graduate Students:			
Joan Anderson	9/78-8/79	Graduate Student	Technical Assistance Delivery System UNC, Chapel Hill, NC
Martha Arnold	10/78-12/80	Free-Lance Educational Media Specialist	Old Hillsborough Road Chapel Hill, NC
*Lynn Baker-Ward	7/78-6/82	Graduate Student	Development Psychology UNC, Chapel Hill, NC
*Paula Beckman-Bell	7/79-6/81	Assistant Professor	Dept. of Spec. Education University of Maryland College Park, MD
*Jan Blacher	9/77-5/79	Assistant Professor	Div. of Spec. Education Dept. of Education University of California Riverside, CA
*Marie Bristol	9/77-12/78	Assistant Director	CIREEH, FPG Center UNC, Chapel Hill, NC
Peg Burchinal	1/79-6/82	Social Research Assistant and Graduate Student	Project CARE, CIREEH FPG Center UNC, Chapel Hill, NC
Judy Burke	8/78-10/81	Law Student	School of Law UNC, Chapel Hill, NC

*Students who also participated in the Frank Porter Graham Child Development Center's Research Training Program

Table 14-1 continued

CIREEH Research Trainees

Name	Dates Affiliated	Current Position	Current Location
Graduate Students:			
Walter Creekmore	2/80-8/80	Assistant Professor	Northeastern Lousiana University Monroe, LA
Dewitt Crosby	9/78-8/79	Recent Ph.D.	711 Clement Charlotte, NC
Art Cross	9/79-5/80	Associate Professor	Dept. of Spec. Education Appalachian State University Boone, NC
Jill Fishbein	8/79-7/81	Pediatric Psychology Intern	School of Medicine University of Maryland Baltimore, MD
Raymond Gallagher	9/78-7/80	Director	Infant Program Illinois Institute for Development Disabilities Chicago, IL
*Sharon Gerber	9/81-5/82	Graduate Student	Developmental Psychology UNC, Chapel Hill, NC
Michael Gerner	9/81-12/81	Consultant	Orange County School Systems Hillsborough, NC

*Students who also participated in the Frank Porter Graham Child Development Center's Research Training Program

Table 14-1 continued

CIREEH Research Trainees

Name	Dates Affiliated	Current Position	Current Location
Graduate Students:			
Ellen Gillespie	9/77-5/79	Associate Director	Dept. of Spec. Education State Dept. of Louisiana Baton Rouge, LA
Jean Gowen	9/77-6/82	Coordinator	CIREEH, FPG Center UNC, Chapel Hill, NC
Sandra Gray	9/79-5/80	Graduate Student	Developmental Psychology UNC, Chapel Hill, NC
Gwen Gustafson	9/78-6/79	Assistant Professor	Dept. of Psychology Northern Illinois University DeKalb, IL
Anne Hocutt	9/78-5/81	Consultant	CIREEH, FPG Center UNC, Chapel Hill, NC
Gail Huntington	11/78-6/82	Research Assistant	CIREEH, FPG Center UNC, Chapel Hill, NC
*Connie Kasari	9/81-6/82	Graduate Student	Special Education UNC, Chapel Hill, NC
Judith Leonard	9/78-5/79	Lawyer	Office of General Counsel, Dept. of Education 400 Maryland Avenue Washington, DC

*Students who also participated in the Frank Porter Graham Child Development Center's Research Training Program

Table 14-1 continued

CIREEH Research Trainees

Name	Names Affiliated	Current Position	Current Location
Graduate Students:			
Marylou Lyon	9/81-6/82	Graduate Student	Special Education UNC, Chapel Hill, NC
*Dave MacPhee	7/79-6/82	Graduate Student	Developmental Psychology UNC, Chapel Hill, NC
Trina Maples	1/81-6/81	Graduate Student	Psychology UNC, Chapel Hill, NC
Thomas Mates	7/80-9/81	Graduate Student	Psychology UNC, Chapel Hill, NC
Love Mills	3/81-5/82	On-the-market	Cincinnati, Ohio
Karen O'Donnell	9/79-8/81	Post-doctoral Fellow	Illinois Institute for Development Disabilities Chicago, IL
*Peggy Ogle	9/80-6/82	Graduate Student	Special Education UNC, Chapel Hill, NC
Susan Parse	1/79-7/79	Director	Early Education Program Olympia, Washington
Jane Perrin	9/79-5/80	Psychologist	Student Health Clinic UNC, Greensboro, NC

*Students who also participated in the Frank Porter Graham Child Development Center's Research Training Program

Table 14-1 continued

CIREEH Research Trainees

Name	Dates Affiliated	Current Position	Current Location
Graduate Students:			
Rebecca Posante-Loro	8/77-8/79	Director	Early Childhood Education State Dept. of Education Baton Rouge, LA
Ann Rhyne	11/79-6/82	Social Research Assistant	Project CARE, CIREEH FPG Center UNC, Chapel Hill, NC
Julie Robinson	9/79-5/80	Unknown	75 Janet Street Jesmund, New South Wales Australia
Dorit Roer-Bernstein	9/80-6/82	Graduate Student	Psychology UNC, Chapel Hill, NC
Carol Schrimp	1/80-12/81	Social Worker	Operation Awareness Fayetteville, NC
Rick Short	10/80-6/82	Research Assistant	FPG Center UNC, Chapel Hill, NC
Clifford Stephens	1/82-6/82	Graduate Student	Clinical Psychology UNC, Chapel Hill, NC
Pam Winton	9/80-6/82	Research Associate	CIREEH, FPG Center UNC, Chapel Hill, NC

Table 14-1 continued

CIREEH Research Trainees

Name	Dates Affiliated	Current Position	Current Location
Graduate Students:			
Janice Wheelon	10/78-12/80	Educational Specialist	FPG Center UNC, Chapel Hill, NC
Keith Yeates	9/81-6/82	Graduate Student	Clinical Psychology UNC, Chapel Hill, NC
Undergraduate Students:			
Debbie Mills	4/81-6/82	Computer Programmer	Data Management Statistical Unit UNC, Chapel Hill, NC

Table 14-2

CIREEH Research Training:

Dissertations and Theses

Name	Title	Date
Dissertations:		
Joan Anderson	Positive and negative affective responses as developmental markers in moderately and severely handicapped infants and toddlers.	1980
Paula Beckman-Bell	A study of the relationship between child characteristics and stress as reported by mothers.	1980
Jan Blacher-Dixon	Social intelligence in early childhood: A diagnostic and comparative study of fundamental communication skills in young retarded and nonretarded children.	1979
Marie Bristol	Maternal coping with autistic children: The effects of child characteristics and interpersonal supports.	1979
Walter Creekmore	The relationship between the development of visual preference and selected affective responses in normal infants.	1979
Art Cross	Parental characteristics of family adaptation to a handicapped child.	1980

Table 14-2 continued

CIREEH Research Training:

Dissertations and Theses

Name	Title	Date
Dissertations:		
Raymond Gallagher	Positive affect in physically handicapped, mentally retarded infants: Its relationship to developmental age, temperament, physical status and setting.	1979
Anne Hocutt	Parent involvement policy and practice: A study of parental participation in early education projects for handicapped children.	1979
Susan McHale	Changes in the play in communicatory behavior of autistic and nonhandicapped children as a function of repeated interaction. Unpublished doctoral	1980
Susan Parse	A comparative study of maternal and professional appraisals of handicapped preschool children.	1979
Rebecca Posante-Loro	Factors related to maternal satisfaction with early childhood education services.	1978
Pam Winton	Descriptive study on parents perspectives of preschool progress: mainstreamed and specialized.	1980

Table 14-2 continued

CIREEH Research Training:

Dissertations and Theses

Name	Title	Date
Dissertations In Process:		
Jean Gowen	Effect of peer presence on creative symbolism of 3- and 5-year old high risk children.	in process
Tom Mates	Siblings of autistic children: The effects of age and sex on home and school adjustment and achievement.	in process
Peggy Ogle	The sibling relationship: Parental perceptions of the nonhandicapped versus the handicapped/nonhandicapped sibling dyad.	in process
Master's Theses In Process:		
Gail Huntington	A study of the relationships between development, behavior, and temperament in infants of three ages.	in process

special emphasis on the care that must be taken in the data reduction and data analysis processes. Many of the students worked with the Frank Porter Graham Child Development Center data management team and thus gained experience in the use of computers for data analysis.

Through attendance at advisory committee meetings and CIREEH staff meetings, knowledge of the research process was augmented by hearing professionals critique each other's work and offer recommendations. Students had opportunities to meet with consultants who were called in for various aspects of the research process. For instance, in the parent involvement project, students and as the investigator met with consultants from the Institute for Research in Social Science regarding the design of survey instruments. Participation in staff meetings at the project level, as well as the general CIREEH staff meetings, provided the students with a first-hand look at the manner in which a large-scale multi-investigator research institute is organized and operated.

The students were also involved in the final step of a research project, that is, reporting of results. They wrote, or assisted in the writing of, 40 publications, gave 34 conference presentations, and co-authored 27 other conference presentations. (CIREEH publications and presentations are listed in Chapter 13 of this report.)

In some of the CIREEH projects, assessment instruments were developed and curriculum materials were created. Students were involved in these projects as well. By participating in instrument development, they learned about writing items, field testing the instruments, and estimating reliability and assessing validity. Students who were involved in the development of curriculum materials learned how to write materials for a specific audience. Experience was also gained in field testing and evaluating the materials and using the results for revising the materials.

In addition to the research activities described above, 11 CIREEH students and post-doctoral fellows were also involved in the Research Training Program at the Frank Porter Graham Center. The Research Training Program is designed for doctoral and post-doctoral trainees who desire special competence in child development at the University of North Carolina at Chapel Hill. Students who are accepted into the Graduate School in their department of choice are eligible for support, provided that they demonstrate excellent scientific promise and a commitment to research in areas related to mental retardation. Although the program includes both doctoral and post-doctoral trainees, the emphasis has been on the doctoral program. Research training at FPG, under this program, has included a combination of practicum experiences, seminars, and internship studies. CIREEH trainees who also participated in the FPG Research Training Program are indicated in Table 14-1.

The multidisciplinary nature of CIREEH is reflected in the fields represented by the students who received research training within the Institute. These students came from the divisions of Special Education, Human Development and Psychological Services, and Curriculum and Instruction in the School of Education. Other students came from the departments of Psychology and Biostatistics, the School of Social Work, and the School of Law. CIREEH has been enriched by the participation of students from these disciplines. For example, the law student assisted with the preparation of guidelines for obtaining informed consent.

Through several series of seminars and colloquia, students receiving training through CIREEH were able to hear presentations by a number of outstanding scholars in the field. For example, through the series of colloquia presented by the Research Training Program they heard presentations by such scholars as Sandra Scarr, Michael and Lisa Wallach, Marion Blank, J. McVicker Hunt, Michael Guralnick, and Richard Bell. The Bush Institute for Child and Family Policy of the Frank Porter Graham Center presented a colloquium series which included such distinguished professionals as Richard R. Nelson, Director of the Institution for Social and Policy Studies at Yale University, and Lois-ellin Datta, Associate Director for Teaching and Learning Programs at the National Institute of Education. Another set of regular meetings at the Frank Porter Graham Center offers the participants, students, and others an opportunity to be informed about ongoing research at the Center. These are the monthly "bag lunch meetings" where people from the Technical Assistance Program and Development Division of the Frank Porter Graham Center, as well as those from the Research Division, update their colleagues on their work.

Three series of seminars were presented by CIREEH. The first series was on assessment and included presentations by CIREEH investigators on a multivariate approach to outcome assessment, a review of parent involvement survey instruments, assessments with high-risk children and their families, methods for studying child development in the network of family and school relationships, and infant curriculum development and assessment instruments. The second series was on CIREEH research on families. Research methods and results were presented and discussed in these seminars regarding the following topics: parent involvement programs for preschool handicapped, parents' role in mainstreaming of preschool handicapped children, families of autistic children, stresses in support systems for families of handicapped children, siblings of handicapped children, and the network of family and school relationships. The third series included a working session on dissemination of results from the family studies, conducted by Joseph Sanders of the FPG Communications Office and the following presentations: "A Sociological Approach to the Study of Families," Dr. Ida Simpson; "Policy Issues in the Care of Handicapped Children: European and American Perspectives," Dr. Robert Moroney; and "Child Care: Cross Cultural Perspectives on the Roles of Extended Kin," Dr. Carol Stack.

In addition to the training activities offered to CIREEH trainees, CIREEH personnel also provided workshops and seminars for other students and practitioners. For instance, 58 students who worked in Dr. Nancy Johnson's Infant Treatment Group at the Division for Disorders of Development and Learning (DDDL) attended a seminar on research implications for intervention with handicapped infants where the curricula for handicapped infants and toddlers developed by Drs. Jens and Johnson was discussed. Workshops have been presented to practitioners on various aspects of CIREEH work. For instance, Dr. Earl Schaefer presented a seminar on "The Validity of Parent's and Teacher's Contributions to Screening for Handicaps" at the Division for Disorders of Development and Learning, the University of North Carolina. Investigators with the curriculum development project have also presented special workshops for students visiting from other universities regarding programming for the severely and multiply handicapped infants.

CHAPTER 15

The Impact of CIREEH on the Field of Early Education for the Handicapped

The question of the impact of a program of research upon clinicians and educational practitioners has been a complex and difficult one. Glaser (1976) indicated that there was a time between innovation and implementation of 19 years, even with such major innovations as hybrid corn, oral contraceptives, or the videotape recorder.

The second major limitation on immediate impact is the size of the enterprise which is targeted. With over 14,000 school districts and over 4 million exceptional children receiving service, the immediate translatability of research to such programs becomes an unlikely event. The question, then, is how should impact be judged?

There are two broad intermediate approaches that would seem to be appropriate. One way in which to estimate the impact the Institute has already had is to examine the level of dissemination that has taken place through publication and distribution of research reports, literature reviews, curricula materials, and assessment instruments and through presentations at conferences and meetings. The second way in which impact can be judged is through feedback the Institute has received from the field regarding utilization of research results, assessment instruments, and curriculum materials. For example, there is evidence that more training programs are including fathers after CIREEH research found that fathers of handicapped children wanted more involvement with their children.

These two approaches can indicate some basic ways in which the research institute is already having, and will continue to have, an impact on the field. In addition to the two limitations described above, there is an additional reservation regarding assessment of the impact of research emanating from any one research project. Research is carried out in the context of a large number of concurrent professional and social trends that may be moving in the same direction. Therefore, the fact that there is a concomitant interest in fathers, for example, cannot necessarily be assigned as an impact of only one particular research program.

Our attempts at analysis of the impact of CIREEH are presented with these reservations in mind. Long-term impact of research programs may not be felt for 10 or 15 years. Even then, the impact will be through a diffuse osmosis of the significant results of the program via the professional literature and, from there, into practice.

Dissemination Activities

CIREEH dissemination activities are described in more detail in Chapter 12 of this report and CIREEH products and conference presentations are listed in Chapter 13.

A review of CIREEH dissemination activities reveals that CIRREH has produced 105 publications and several assessment instruments and sets of curriculum materials. Approximately 150 HCEEP projects receive regular communications from CIREEH as part of the FPG Center's national mailings; these mailings bring information about CIREEH to more than 20,000 readers. Information released regularly includes the *Developments* newsletter, CIREEH abstracts of scholarly articles, the *CIREEH Status Report* of the FPG Center (which contains a section devoted to CIREEH). Over 22,000 copies of publications containing information about CIREEH have been distributed from the Communications Office. In addition, the Communications Office staffed display booths at two national conferences for the purpose of distributing materials from all four early childhood research institutes.

In addition to these printed products, CIREEH has informed a wide variety of audiences about its research findings through 193 presentations at conferences and other meetings.

In the next section, feedback regarding CIREEH impact which has been received by CIREEH investigators will be discussed.

Successful Parents Project

The results of this research have been presented to consumer groups in both written form (i.e., articles and reports) and in oral presentations through major conferences on the handicapped child. The key findings that seemed to have had impact were the special problems of the father's role in families of handicapped children. Both fathers and mothers appeared to be un-able to find specific ways to play a more active role.

The second finding that seemed to have had some effect, as indicated by the response of conference participants and in subsequent correspondence, was a discovery of a rather traditional role pattern in families of handicapped children. These families deviated little from the pattern expected in families of nonhandicapped children. In short, there appears to be no dramatic realignment of responsibilities that is apparent in the families of handicapped children. This may indicate that we, as professionals, are spending more time concerned with the dramatic adjustments the family has to make in coping with a handicapped child without realizing that the family basically appears to make only minor adjustments to this event, at least as long as the child is of preschool age.

The third major aspect of this project which appears to have had impact on the field is the assessment instrument which was developed, the Parent Role Scale. Even in pilot form, it has attracted a great deal of attention. The Parent Role Scale charts the allocation of responsibilities, on the part of the father and mother. There have been several requests for the use of the Parent Role Scale. We have delayed distributing them in wider form pending modest revisions of the items and more validation data. We have also developed a "one-parent" form that we think has now been pilot tested sufficiently to be usable.

Reprints and reports of research results from this project have been distributed to the Handicapped Children Early Education Program Network. These have contributed in some small way, we think, to the revival of interest in the role of the father within the framework of programs for preschool handicapped children. It is difficult, particularly, on this short-range basis, to measure long-term impact when this is merely one study in a growing body of studies which have the father as the focus of attention.

Parent Involvement Project

Research activities in this project were designed to accomplish the following objectives: (1) define and describe parent participation activities through the use of a typology of activities; (2) examine the roots of current efforts to involve parents of handicapped children in program activities; (3) interpret current legislative efforts to support parent involvement; (4) assess parent satisfaction of involvement; and (5) measure the extent to which parents are involved in early education programs in the HCEEP First Chance programs. The results of this research have been disseminated to a wide variety of audiences which have been able to utilize this information for diverse purposes as follows: (1) to project directors to assess and further develop their programs; (2) to policy makers and administrators to further understand the impact of policies and national trends in parent involvement; (3) to researchers who have investigated and evaluated instances of parent involvement; and

(4) to interested professionals and citizens who have been affected by parent participation programs.

Invited papers by Ron Wiegerink, principal investigator, to the Minnesota Roundtable on Early Education, the Napa Valley Early Childhood Conference in California, West Virginia Conference in Early Education, and the Louisiana Special Education Conference during the last year demonstrate the breadth and level at what the findings are being communicated. The movement in the field of early education toward more parent involvement and more varieties of parent involvement parallels the work of the CIREEH studies. Dissemination during the early years of CIREEH (1977-1978) at national meetings served to stimulate and later reinforce this pattern of increased parent involvement. Active use of the Parent Involvement Instrument and results and continuing communication with early childhood projects attest to the interest generated by this program of research.

Families At Risk Project

Since this project did not begin until Year Three of the Institute, it is a bit premature to try to judge its impact. Only one chapter has been out long enough to be reviewed [Parent Involvement (with R. Wiegerink) in M. Paluszny (Ed.), *Autism: A Practical Guide for Parents and Professionals*]. The chapter was favorably reviewed in both the *American Journal of Mental Deficiency* and the *Journal of Autism and Developmental Disorders*. The book has gone from a hard cover printing into paperback because of the demand. The National Society for Autistic Children recommends it as a primary nontechnical text on autism.

It is hoped that the 1,000 copies of *Autistic Children in Public Schools* (Schopler & Bristol, 1980) distributed by the Council for Exceptional Children to regular and special classroom teachers and administrators will assist families of autistic children by increasing understanding of child and family needs.

The number of requests for presentations on the project's research is another measure of the impact of this project. The investigator has spoken to over 1,400 parents, teachers, psychologists, administrators, physicians, state department personnel, and researchers. When formal evaluations were available, they have been extremely favorable. Numerous requests for papers and for additional presentations have been received. Within the last two months, Dr. Bristol has been requested to present papers or workshops for several state departments of education (e.g., Louisiana, Oklahoma, North Carolina), parent service delivery programs (e.g., Cleveland), parent organizations (e.g., National Society for

Autistic Children), and research groups. A report on this project's research is one of 27 invited papers for the Invitational Conference on Environments for Developmentally Disabiled Persons to be co-sponsored by NICHHD and the University of Washington. Two invited presentations have already been scheduled for next year.

Family Relations Project

Almost 200 requests have been received by this project for copies of the assessment instruments developed in this project. Several other copies have been distributed at meetings.

The Parent As Educator Inventory is now being used by graduate students at Yale University, Rutgers University, and Little Rock University. The preschool version of the Classroom Behavior Inventory has been used in education classes at Durham Technical Institute and by Special Services for Children in Raleigh. The Sibling Inventory of Behavior is being used in at least two research studies at the University of North Carolina. A recent call from Ypsilanti, Michigan requested five of the assessment instruments for possible use in a study of the second generation in the Perry Preschool Project. Copies of instruments have been requested by researchers in New Zealand, Germany, Australia, and Jerusalem.

Child Assessment Project

This project can be summarized as having an impact in three areas: scholarly exchange, practitioner exchange, and personal contacts. In regard to scholarly exchange, 14 publications have been prepared on different aspects of early intervention research and practices. Of these, two are chapters in books, and 12 are articles appearing in the periodical literature. In addition, 17 presentations have been made at meetings of professional societies where the audiences primarily consisted of researchers and scientists. In the area of practitioner exchange, the major activities have been in the dissemination of information to various practitioners serving young handicapped children. In this regard, 11 presentations have been made at meetings and conventions of practitioner groups, and four presentations were made in response to specialized topical conferences.

The third area of impact is represented by personal contact in which individuals have made direct contact with this project for specific information about assessment strategies and instruments.

Curriculum Development Project

There is a reasonable amount of evidence that the curriculum development project for severely/multiply handicapped young children has had a positive impact on a large number of programs serving handicapped children throughout the United States, several of its territories, and at least three foreign countries. The authors of the curriculum have been requested to make presentations at eight to ten regional and national conferences per year regarding use of the curriculum. Requests for copies of it, and for information regarding when it will be available commercially, continue to come in on a regular basis.

An HCEEP project in Louisiana has requested and obtained permission to use the essential curriculum model incorporated into the Carolina Curriculum for Handicapped Infants for the development of its own curricular materials for distribution throughout the state of Louisiana.

A statement included in the product dissemination booklet of the U.S. Office of Education market linkage project indicated that there was "a definite need for this product--this is a good curriculum for all children, not just for handicapped children--it is well organized and useful, and . . . the developmental profile is especially good."

Field testing of the curricular materials is in progress and information received thus far indicates that persons using it as a basis for intervention find it both highly useful and easy to use.

Project CARE

At least three projects are using the design and/or curriculum of Project CARE as a model for their programs. The Robert Wood Johnson Foundation and the Administration for Children, Youth, and Families are currently investigating the possibility of establishing a network of sites dealing with prevention, based on the knowledge they have gained from Project CARE. Joy Osofsky at the Menninger Foundation is beginning a study using Project CARE as a model. An intervention program for children with cerebral palsy, currently being conducted at the J. F. Kennedy Center at Johns Hopkins, is using Learningames as their curriculum, and several other projects around the country use Learningames in combination with other curricula.

A group of three researchers from the University of Washington's National Center for the Assessment of Delinquent Behavior and its Prevention recently spent two days with Project CARE's staff. They sought information about our research procedure, delivery system, and organizational set-up. Their purpose was to get information and materials from our project to use in their early intervention program, a longitudinal study of delinquency being carried out in six school systems throughout the country.

In terms of instrument dissemination, two graduate students at other universities are using the Parent Problem Solving Instrument in the dissertation research.

Parents' Perspectives on Preschool Mainstreaming

The results from the studies of parents' perspectives on preschool mainstreaming have made an impact in three areas: research, practice, and policy.

Presentation of CIREEH research data stimulated a researcher at Cleveland State University to conduct an interview study on preschool mainstreaming with a sample oh mothers in the Cleveland, Ohio area. The results of this study substantiated many of the findings on preschool mainstreaming from CIREEH studies. In addition, the two-phased interview strategy used in one of the parent studies has been adapted for use by the Bureau of Child Research at the University of Kansas in a study of Impact of Families on the Development of Independence in Disabled Adolescents and adults.

The data which has had the greatest impact on practice and policy is that on parents' perspectives on parent involvement in preschool programs. Requests for papers in this topic have outnumbered requests for papers on mainstreaming. After conference presentations of this data, practitioners and parents in the audience have frequently come forward to express how this data validates their own experiences. Some practitioners commented that this data shed light on why their own parent programs were not as "successful" as they felt they should be. There were judging "success" in terms of a "body count" and were frustrated when parents did not come to activities. Their comments indicated that they were going to work towards individualizing for families and broadening their criteria for a successful parent program. Partially as a result of articles generated from this data on parents' perspectives on involvement, Ann and Rud Turnbull have been asked to edit an issue of *Exceptional Child Quarterly*, devoted to an analysis of parent invovlement policy.

Results of this project's efforts have resulted in 17 publications and have been reported at 20 conferences.

Appendix A

Evaluation Procedures Used in Project CARE

This description of the evaluation instruments used in Project CARE is organized chronologically and by column in correspondence with Table 3 in the text. The instruments are as follows:

1. The Demographic interview is an interview in which current information is collected about major demographic characteristics of the mother and child. This includes the mother's and father's present occupation, income, educational level, and marital status. In addition, the mothers are asked about the type and amount of day care their child has received. This information is collected annually, when the child is 6, 18, 30, 42, and 54 months-of-age.

2. The pregnancy and birth records are collected from the hospital in which the baby was born. The records are used by Project CARE to identify premature babies and/or children with prenatal or perinatal problems.

3. The Infant Behavior Record provides a description of the infant's characteristic behavior patterns as observed during the administration of the Mental and Motor Scales of Bayley Scales of Infant Development (Bayley, 1969). The IBR consists of a number of descriptive rating scales for behaviors characteristic of children up to 30 months of age. These scales include the child's interpersonal and affective domains, motivation variables, and the child's interest in specific modes of sensory experience.

4. The Infant Temperament Questionnaire (ITQ) (Carey & McDevitt, 1978) is a questionnaire that asks the mother about her infant's typical behavior. It is designed to measure the infant's personality and temperament. The ITQ consists of nine scales: activity level, rymthicity, distractibility; approach-withdrawal, adaptability, persistence, threshold of responsiveness, intensity of reaction, and mood.

5. The Reciprocal Control Coding System (Farran & Haskins, 1980) is used to code the behaviors of the mother and her child during a 20-minute free-play session videotaped in a laboratory setting. The codes include measures of the types and level of activities of each dyad member and of their responsiveness to each other.

6. *The teaching task* is a 6 to 8-minute videotaped situation in which the mother has been asked to teach her child a task. The tasks vary with the age of the child. At 6 months the task is to learn to reach around a barrier for an object. At 12 and 18 months, the task is an imitation game. At 36 months, the task is to learn a complicated pegboard. At 60 months, the task is to match shapes and lengths of blocks. The mothers' behavior in these sessions is rated using a 35-question rating scale with items concerning directiveness, verbal skills, pacing, and responsivity.

7. *Caldwell's Inventory of Home Stimulation* (Caldwell, Heider, & Kaplan, 1966) was designed to assess the quality and quantity of social, emotional and cognitive support for the young child within his home environment. The questionnaire is completed by a visitor to the home. The scale is divided into various subscales: maternal warmth, absence of punishment, organization of environment, provision of appropriate toys, maternal involvement with child, and opportunities for variety.

There are 7 subscales in the version used on visits to homes of 3-6 year-olds. These are equipment, toys, experience; stimulation of mature behavior; physical and language environments; avoidance of restriction; pride, affection and thoughtfulness, masculine stimulation; and independence from parental control.

8. The *Parental Attitude Research Instrument* (Emmerich's 1969 version of Schaefer & Bell's 1958 original) is a questionnaire designed to measure mothers' attitudes about child-rearing. The inventory produces scores on three factors: authoritarian control, hostility-rejection, and democratic attitudes.

9. *Rotter's Internality-Externality Scale* (Rotter, 1966) is a questionnaire designed to measure the extent that an individual believes herself to be in control of the direction which her life is taking, that is, the locus of control.

10. *Growth measures*. The children's height, weight, and head circumference, are measured every 6 months. This is collected to monitor physical growth and development.

11. The *Toddler Temperment Scale* (Fullard, McDevitt, & Carey, 1978) is the version of the ITQ used for toddlers. It is administered in the same manner and has the same 9 subscales (see number 4 of this Apepndix).

12. The *Ainsworth Strange Situation* procedure (Ainsworth & Wittig, 1969) is conducted to measure the strength of the attachment bond of a child for his mother. It is a videotaped laboratory situation with various combinations of mother, child, and stranger in the room. The tapes are coded using Ainsworth's established coding system.

13. The *Community Interaction Checklist* (CIC) (Wahler, Leske, & Rogers, 1979) is a parent self-report measure that reflects parent insularity. The CIC is a means of prompting parent recall of extra-family social interactions over the past 24 hours. The parent is asked to recall all social contacts, the identity of the contact person (ex., friend, kinfolk, helping agency), who initiated the contact (self or other), valence of the contact (+3=great to -3=very bad), and a number of other characteristics about the interaction. The CIC was administered to each mother six times between 6 and 12 months and six times between 20 and 24 months.

14. The *Supports Interview* was developed by Project CARE and was conducted with each mother when she had completed the first six CICs. From a list of 135 local service agencies, a mother was asked to identify each one if she could. If she had contacted that agency in the past year, she reported the number of times and how she would rate the services provided (on a scale of +3 to -3). The mother was then presented with a series of hypothetical problems and asked which agency(ies) could help solve that problem. The last part of the Supports Interview consisted of asking the mother to draw a sociogram of important people in her life, to rank order those people, give their ages, frequency of contact, and what type of childrearing help, if any, was provided by each of the people on the sociogram.

15. The *Parent Problem Solving Inventory* (PPSI) developed in Project CARE (Wasik, Bryant, & Fishbein, Note 12) is a method of measuring means-end problem solving thinking. Ten parenting problem situations are presented to a mother and a predetermined outcome is given for each situation. The subjects' task is to generate alternate solutions for achieving the given outcome. A verbatim transcript of the mothers' responses is made and the type and number of responses is coded.

16. The *Inventory of Caregiver's Child Development Values and Concepts* (Gowen & Gustafson, 1980) is administered to each mother when her child is 20 months of age. The mother is asked to assign a value, ranging from very important to not important at all, to a series of child-rearing and educational activities depending on whether she thinks each activity is important for the development of various skills. These skills range from linguistic development to general child development. Overall scores for these areas are computed.

17. The *Kohn and Rosman Behavior Rating* (Kohn and Rosman, 1972) is completed by the experimenter after she has administered a Stanford-Binet or McCarthy test to a child. This rating system includes questions about the child's behavior in the testing situation, including confidence, friendliness, anxiety, attention, and cooperation.

18. The *Stanford-Binet Intelligence Scale* (Terman & Merrill, 1973) is administered individually to each child when the child is 24-, 36-, 48-, and 60-months of age to assess the child's intellectual development.

19. The McCarthy Scales of Children's Abilities (McCarthy, 1970) is administered individually to each child when the child is 30-, 42-, and 54-months of age to assess the child's differential development in primary cognitive skills such as verbal, perceptual-performance, quantitative, memory, and motor development.

20. Parent Evaluation of Program. When their child is 30-months old, mothers are asked to complete a short questionnaire evaluating various aspects of the day care or parent education programs. This is for internal evaluation. They are also asked about their long-term goals for their child.

21. The Knowledge of Infant Development Inventory (MacPhee, 1980) is a questionnaire given to the mothers to complete when their children are 30-months-old. Mothers are asked whether they agree with statements about the behavior of a "typical" infant and what could affect a baby's growth and behavior. Items are be grouped into 4 subscales: norms and milestones; principles; parenting; health and safety. These scores are calculated for each mother.

22. The Modified Schedule of Recent Experience (Holmes & Rahe, 1967) is administered to mothers by an experimenter when their children are 3, and 36, and 60 months old. Mothers are asked to report which of various social events requiring change in ongoing life adjustment had occurred in their lives during the past year. A stress index is calculated by assigning weights to items and summing them.

23. The Attitude Questionnaire administered at 30 and 60 months is a combination of items developed by Schaefer and Edgerton (1977). It was designed to determine childrearing and educational attitudes.

24. The Wechsler Preschool and Primary Scale of Intelligence (WPPSI). Wechsler (1967) developed the WPPSI for use with children aged 4 to 6 1/2 years. It is a separate and distinct scale, although similar to the WISC in form and content.